

Final Technical Brief

Number xx

Evidence Map on Home and Community-Based Services and Person-Centered Care for Older Adults

Prepared for:

Agency for Healthcare Research and Quality
U.S. Department of Health and Human Services
5600 Fishers Lane
Rockville, MD 20857
www.ahrq.gov

Contract No.: 75Q80120D00005/75Q80123F32004

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AHRQ Publication No. xx-EHXxxx
September 2024

This report is based on research conducted by the Mayo Clinic Evidence-based Practice Center (EPC) under contract to the Agency for Healthcare Research and Quality (AHRQ), Rockville, MD (Contract No. 75Q80120D00005/75Q80123F32004). The findings and conclusions in this document are those of the authors, who are responsible for its contents; the findings and conclusions do not necessarily represent the views of AHRQ. Therefore, no statement in this report should be construed as an official position of AHRQ or of the U.S. Department of Health and Human Services.

None of the investigators have any affiliations or financial involvement that conflicts with the material presented in this report.

The information in this report is intended to help decision makers, participants, patients, health system leaders, and policymakers, among others—make well-informed decisions and thereby improve the quality of home and community-based services (HCBS) for older adults and older adults with disabilities. The focus of this review is on older adults and adults with disabilities as a result of the funding source, which is the Older Americans Act funding from the Administration for Community Living, which funds services and supports for adults over 60 who have the greatest economic and social need. The vast majority of HCBS are provided through Medicaid, and this review is focused on older adults who receive Medicaid HCBS to understand any potential implications for populations ACL serves. Anyone who makes decisions concerning the provision of clinical care should consider this report in the same way as any medical reference and in conjunction with all other pertinent information, i.e., in the context of available resources and circumstances presented by individual patients.

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AHRQ appreciates appropriate acknowledgment and citation of its work. Suggested language for acknowledgment: This work was based on an evidence report, Evidence Map on Home and

Community-Based Services, by the Mayo Clinic Evidence-based Practice Center Program at the Agency for Healthcare Research and Quality (AHRQ).

Suggested citation: Wang Z, Chen CYY, Njeru JW, Nayfeh T, Saadi S, Viola KE, Prokop LJ, Murad MH. Evidence Map on Home and Community-Based Services. [Technical Brief] No. #. (Prepared by the Mayo Clinic Evidence-based Practice Center under Contract No. 75Q80120D00005/75Q80123F32004.) Rockville, MD: Agency for Healthcare Research and Quality. September 2024. Available at: www.effectivehealthcare.ahrq.gov/reports/final.cfm

PREPUBLICATION FINAL

Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of healthcare in the United States. The Administration for Community Living requested this report from the EPC Program at AHRQ. AHRQ assigned this report to the following EPC: Mayo Clinic Evidence-based Practice Center (Contract Number: 75Q80120D00005/75Q80123F32004). The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new healthcare technologies and strategies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

This EPC evidence report is a Technical Brief. A Technical Brief is a rapid report, typically on an emerging medical technology, strategy or intervention. It provides an overview of key issues related to the intervention—for example, current indications, relevant populations and subgroups of interest, outcomes measured, and contextual factors that may affect decisions regarding the intervention. Although Technical Briefs generally focus on interventions for which there are limited published data and too few completed protocol-driven studies to support definitive conclusions, the decision to request a Technical Brief is not solely based on the availability of clinical studies. The goals of the Technical Brief are to provide an early objective description of the state of the science, a potential framework for assessing the applications and implications of the intervention, a summary of ongoing research, and information on future research needs. In particular, through the Technical Brief, AHRQ hopes to gain insight on the appropriate conceptual framework and critical issues that will inform future research.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the healthcare system as a whole by providing important information to help improve healthcare quality.

If you have comments on this Technical Brief, they may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 5600 Fishers Lane, Rockville, MD 20857, or by email to epc@ahrq.hhs.gov.

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The authors gratefully acknowledge Task Order Officers Angela Carr, D.Soc.Sci., M.H.A., R.N., and Lionel Bañez, M.D., from the Agency for Healthcare Research and Quality and Amanda Cash, Dr.Ph., M.P.H., and Shawn Terrell, M.S., M.S.W., from the Administration for Community Living for their contributions to this project.

Key Informants

In designing the study questions, the EPC consulted a panel of Key Informants who represent subject experts and end-users of research. Key Informant input can inform key issues related to the topic of the technical brief. Key Informants are not involved in the analysis of the evidence or the writing of the report. Therefore, in the end, study questions, design, methodological approaches and/or conclusions do not necessarily represent the views of individual Key Informants.

Key Informants must disclose any financial conflicts of interest greater than \$5,000 and any other relevant business or professional conflicts of interest. Because of their role as end-users, individuals with potential conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any conflicts of interest.

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Prior to publication of the final evidence report, EPCs sought input from independent Peer Reviewers without financial conflicts of interest. However, the conclusions and synthesis of the scientific literature presented in this report do not necessarily represent the views of individual reviewers. AHRQ may also seek comments from other Federal agencies when appropriate.

Peer Reviewers must disclose any financial conflicts of interest greater than \$5,000 and any other relevant business or professional conflicts of interest. Because of their unique clinical or content expertise, individuals with potential non-financial conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any potential non-financial conflicts of interest identified.

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Evidence Map on Home and Community-Based Services and Person-Centered Care for Older Adults

Structured Abstract

Background. People who receive home and community-based services (HCBS) have diverse and unique needs that can be met with these services aiming to support their independence.

Purpose. To map the existing literature on HCBS in terms of interventions, populations, outcomes, person-centeredness, and relevant quality measures, and identify research gaps for older adults.

Methods. A comprehensive literature search of multiple databases including Medline, Embase and Scopus was conducted up to December 7, 2023, and complemented with grey literature search and feedback from Key Informants. Eligible studies evaluated HCBS interventions in adults aged 60 years or older with a functional limitation requiring assistance with activities of daily living.

Findings. We identified 27 primary studies, 25 systematic reviews, and 29 quality measures. The most common types of interventions evaluated in HCBS studies involved optimization of person-centered planning, nonpharmacological approaches for dementia care, physical rehabilitation, collaborative care models, home-based palliative care programs, home healthcare via telehealth, self-directed home care, geriatric resources for practical support at home, interdisciplinary care coordination for high-risk conditions and delivery of specific services. Populations studied in HCBS studies included those with functional disability, cognitive impairment, high-risk/frail conditions, and people with specific conditions, most commonly Parkinson's disease, Alzheimer's disease, or end-stage kidney disease. Person-centered planning and self-direction of HCBS services were not explicitly described in most of the primary studies and very few of these studies focused on addressing health-related social needs, whereas the majority had primary outcomes that can be considered medical or clinical. Numerous quality measures exist for HCBS. Some of them are validated, address multiple person-centered domains, and can apply across various conditions and populations. Key challenges in the literature on HCBS include lack of randomized trials, inadequate descriptions of interventions to determine person-centeredness, and limited information on facilitators and barriers. Because of the variability in how person-centeredness is operationalized in HCBS interventions, Key Informants reinforced the need to evaluate person-centered outcomes as a quality indicator of HCBS interventions. Key Informants also highlighted workforce challenges in recruiting, retaining, and training personnel delivering HCBS.

Conclusion. This evidence map summarizes the HCBS literature in terms of interventions, populations, outcomes, and relevant quality measures for older adults and older adults with disabilities.

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Executive Summary

Main Points

- The types of interventions evaluated in home and community-based services (HCBS) studies involved optimization of person-centered planning, nonpharmacological approaches for dementia care, physical rehabilitation to improve function, collaborative care models, home-based palliative care programs, home care via telehealth, self-directed home care, geriatric resources for practical support at home, and delivery of specific services (e.g., skilled nursing, physical therapy, occupational therapy, home health aide, and case management).
- Although most HCBS serve people with disabilities across the lifespan, this Technical Brief focused on older adults with and without disabilities. Populations studied in HCBS literature included those with functional disability, cognitive impairment, high risk/frail conditions, and people with specific conditions, most commonly Parkinson disease, Alzheimer disease, or end-stage kidney disease.
- Outcomes evaluated in HCBS studies can be categorized as clinical outcomes (surrogate and final outcomes), person-centered outcomes, caregiver outcomes, utilization outcomes, and economic outcomes.
- The available literature had a focus on medical interventions with less focus on health-related social needs, such as housing, transportation, and nutrition.
- Determining whether a published study used a person-centered intervention or how involved individuals receiving HCBS were in selecting and using the services they received was not explicitly described in most of the available publications.
- Few studies evaluated person-centered outcomes, quality-of-life, satisfaction, social isolation, or caregiver outcomes.
- Tokenistic use of the term person-centered in the literature is possible and hard to ascertain. Therefore, in addition to using person-centeredness as a characteristic of HCBS interventions, it may also be considered as a quality indicator of the intervention to assure fidelity to this concept.
- Factors that potentially affect HCBS interventions include a person's demographics and level of disability; the knowledge, skills and training of caregivers and providers; the person-centeredness of the intervention; level of multidisciplinary teamwork and coordination; and providers' organizational process and culture.
- Determining whether person-centeredness impacted the effectiveness of HCBS interventions was not possible.
- Numerous quality measures exist for HCBS. Some of them are validated, address multiple person-centered domains, and can apply across various conditions and populations.

Background and Purpose

HCBS are services and supports that assist older adults and people with disabilities (including mental health and substance use disorders) to live independently in home and community settings.^{1, 2} One in four adults in the United States have a disability that impacts their cognitive function, physical function, and independence.³ HCBS are an array of person-centered services delivered in the home and community and are considered as a means to improve the lives of people with functional limitations to keep them living independently and safely in the community. A variety of services and interventions are available to prioritize individual needs, preferences, and goals that aim to enhance well-being, quality of life, and

independence. While some of these services can be perceived as medical, such as the management of a chronic medical condition at home, many are not medical and can include various types of person-centered services targeting health-related social, logistical, and legal needs (e.g., advance directives for health care). Person-centered planning and self-direction are key components of HCBS. Person-centered planning is a process, “for selecting and organizing the services and supports that an older adult or person with a disability may need to live in the community.”⁴ Importantly, it is a process that is directed by the person who receives the support.” Self-direction implies a consumer-controlled method of selecting and using services allowing the person’s maximum control over HCBS including the amount, duration, scope of services and choice of providers.^{1, 2} Services that address unmet social needs, such as housing, transportation, nutrition, and employment, are increasingly recognized as an essential part of HCBS.⁵ Conceptually, person-centeredness is a value structure rooted in the universal concepts of human and civil rights and is critical for delivering HCBS interventions.

This Technical Brief provides an evidence map that summarizes service categories of HCBS and describes the research on the interventions and populations have been studied and quality measures proposed for HCBS. This Technical Brief also identifies gaps in the evidence base.

Methods

We used methods consistent with those outlined in the AHRQ EPC Program Methods Guidance (<https://effectivehealthcare.ahrq.gov/products/collections/cer-methods-guide>). We interviewed eight Key Informants (KIs) representing perspectives from Area Agencies on Aging, Federal agencies, HCBS providers, HCBS researchers, and beneficiary advocates (individuals representing/advocating for people receiving HCBS). We searched Embase®, Epub Ahead of Print, In-Process & Other Non-Indexed Citations, MEDLINE® Daily, MEDLINE®, Cochrane Central Registrar of Controlled Trials, Ovid® Cochrane Database of Systematic Reviews, and Scopus® from January 2000 to December 2023. We included studies evaluating the effectiveness of person-centered HCBS interventions and related quality measures. Details of the methodology can be found in the full report.

Results

We summarized the key findings by the Guiding Questions.

Guiding Question 1: Describe the Available Research on the Effectiveness of Person-Centered HCBS Interventions, for Adults Aged 60 or Older with a Functional Limitation in Home and Community-Based Settings.

Findings: We included 27 primary studies and 25 systematic reviews. The studied interventions included efforts towards: (1) person-centered planning; (2) integrated/nonpharmacological approaches for dementia care/Alzheimer’s disease; (3) impact of physical rehabilitation on function; (4) benefits of specific services (e.g., skilled nursing, physical therapy, occupational therapy, home health aide use, case management); (5) collaborative care models; (6) home-based palliative care programs; (7) home care via telehealth; (8) implementation of geriatric resources for practical support at home and interdisciplinary care coordination surrounding high-risk transitions, such as posthospital discharge periods; (9) self-directed home care; and (10) unmet health-related social needs.

The study populations can be generally categorized to those with functional disability, cognitive impairment, high risk/frail conditions, and several disease-specific conditions. Very few studies evaluated specific populations such as those who were veterans, immigrants, experiencing homelessness, or have had a substance use disorder. Commonly reported outcomes were medical or clinical, such as hospital admission/readmission, emergency department visits, mortality, clinical outcomes, and functional outcomes. Other outcomes were reported in a few studies including quality-of-life, satisfaction, person-centered outcomes (e.g., choice and control in daily activities), and social isolation. Effect modifiers that were significantly associated with outcomes were intensity of HCBS interventions, individuals' age, gender, marital status, education level, household income, insurance status, limitation of activities of daily living, and social isolation. Factors that might facilitate HCBS implementation include knowledge, skills, and related education/training of caregivers and providers; communication and relationship building; person-centeredness of the intervention; multidisciplinary teamwork and coordinated care; autonomy of older people and independence; and providers' organizational process and culture. The available literature had a focus on medical interventions and outcomes with less focus on health-related social needs, such as housing, transportation, and nutrition. Determining whether a published study used a person-centered intervention or how involved individuals receiving HCBS were in selecting and using the services they received was not explicitly described in the majority of available publications.

Guiding Question 2: What Quality Measures Related to Person-Centered HCBS Interventions Exist or Are Under Development?

Findings: We identified 29 existing quality measures related to person-centered HCBS interventions. These quality measures apply to a broad range of HCBS interventions and populations without restricting to a specific type of intervention or specific disabilities. A few quality measures were developed for a specific geographic location (e.g., a specific State program). These quality measures were developed to benchmark HCBS performance at State, agency, or provider level. Most of the quality measure data are collected through survey questionnaires by telephone or in-person interviews. Through discussions with Key Informants and grey literature searches, we identified three sets of person-centered HCBS quality measure that are currently under development.

- Shirley Ryan AbilityLab RRTC HCBS outcomes
- HCBS outcomes by the National Quality Forum and the California Community Living Network
- The Lewin Group, the National Committee for Quality Assurance, Qlarant, George Washington University and DMA Health Strategies

Guiding Question 3: Describe the Gaps That Exist in the Current Research

Findings: Person-centered planning approaches lacked rigorous research that identifies the target population and conditions under which the most benefit can be attained, as well as quality measures that adequately capture the construct of person-centeredness. These areas can be target for future studies. Few studies evaluated person-centered outcomes, quality of life, satisfaction, social isolation, and caregiver outcomes. These outcomes, along with health-related social needs should be emphasized in future research. Importantly, we did not find studies on caregiver outcomes (i.e., outcomes affecting family members and friends who provide direct care to older and disabled individuals who may suffer burnout and other adverse outcomes). Evidence is lacking on direct care worker recruitment, training and

retention, and on populations traditionally considered to experience health disparities by factors such as race, ethnicity, English language proficiency, gender identity or sexual orientation, and immigration status. Individuals' safety and vulnerability, especially within the home setting, where there may be minimal supervision, represents another area where evidence is needed.

Limitations

Key limitations of the literature on HCBS relate to the difficulty in determining the extent of person-centeredness in the described interventions and the limited information on barriers and facilitators. Definitions of person-centeredness vary, and labeling an intervention as such may be a tokenistic approach in some cases. Analysis of existing definitions suggests the need for person-level elements, such as individuality (care addressing a person's priorities, concerns, and goals based on their experience); provider-level elements such as training and characteristics of healthcare providers (e.g., knowledge, skills, communication); and system-level elements, such as its structure and culture.

In terms of facilitators and barriers, HCBS interventions are complex interventions, involving multiple healthcare and social service professionals and various intervention components. The current literature does not explicitly evaluate HCBS with a complex intervention lens that focuses on interactions, effect modifiers, and the necessary and sufficient components of the intervention.

Implications and Conclusions

This report describes the available literature about HCBS in adults aged 60 years or older with a functional limitation. Overall, the size of the available evidence is small despite the large impact and importance of the issue. The concepts of person-centered planning and self-direction of services in home and community settings have been defined by various authorities and agencies and delivered in many communities, with several available quality measures. However, the research is clearly lagging and remains focused on a medical context as opposed to addressing health-related social needs, which are critical for HCBS recipients to live with dignity and independence in their communities.

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1.Introduction

1.1 Background

Home and community-based services (HCBS) are services and supports that assist older adults and people with disabilities (including mental health and substance use disorders) to live independently in home and community settings.^{1, 2} The majority of HCBS is funded through Medicaid. HCBS are an array of person-centered services delivered in the home and community and are considered as a means to improve the lives of people with functional limitations (i.e., requiring assistance with activities of daily living) to keep them living independently and safely in the community. A variety of services and interventions are available to prioritize individual needs, preferences, and goals that aim to enhance well-being, quality of life, and independence. While some of these services can be perceived as medical, such as the management of a chronic medical condition at home, many are not medical and can include various types of person-centered services targeting health-related social, logistical, and legal needs (e.g., advance directives for health care).

Person-centered planning and self-direction are key components of HCBS. Person-centered planning is a process, “for selecting and organizing the services and supports that an older adult or person with a disability may need to live in the community.”³ Importantly, it is a process that is directed by the person who receives the support.” Self-direction implies a consumer-controlled method of selecting and using services allowing the person maximum control over HCBS including the amount, duration, scope of services, and choice of providers.^{1, 2} Services that address unmet social needs, such as housing, transportation, nutrition, and employment, are increasingly recognized as an essential part of HCBS.⁴

The aging population has diverse and unique complexities that pose a challenge to evaluating HCBS care plans. These complexities arise from numerous factors including variations in medical needs, functional limitations, and social and environmental influences. In addition, supporting housing, transportation, nutrition, and employment, is increasingly recognized as an essential part of HCBS.⁴

1.2 Purpose of This Technical Brief

This Technical Brief provides an evidence map that summarizes service categories of HCBS, describes the research on the interventions and populations that have been studied, and describes the quality measures proposed for HCBS. This Technical Brief also identifies gaps in the evidence base. While the focus of this report is on person-centered HCBS, the guiding questions and literature search included HCBS interventions that were not necessarily labeled as such to not restrict eligible literature. We defined HCBS broadly to include programs developed by states as well as programs developed by researchers and healthcare systems.

1.3 Guiding Questions

This Technical Brief was guided by the following Guiding Questions (GQs):

1. Describe the available research on the effectiveness of person-centered HCBS interventions, for adults aged 60 or older with a functional limitation in home and community-based settings.

1. Introduction

- a. What HCBS interventions have been studied in relation to person-centered approaches?
 - i. For which person-centered HCBS interventions are systematic reviews available?
 - ii. For which person-centered HCBS interventions are sufficient primary research studies available to justify a new systematic review?
 - b. What populations have been studied with person-centered HCBS interventions?
 - c. What primary outcomes of person-centered HCBS interventions have been studied?
 - d. What effect modifiers have been identified in the literature that could affect outcomes such as the presence of unpaid family caregivers as part of the overall care team?
 - e. What study designs have been used to evaluate the effectiveness of person-centered approaches to HCBS interventions?
2. What quality measures related to person-centered HCBS interventions exist or are under development?
 3. Describe the gaps that exist in the current research.
 - a. Which person-centered HCBS interventions identified by experts as currently relevant have no or inadequate evidence?
 - b. Which patient populations and outcome measures have no or inadequate evidence?
 - c. Are there gaps in evidence related to taking person-centered planning approaches to these interventions?

2. Methods

2. Methods

We followed the established methodologies of Technical Briefs as outlined in the Agency for Healthcare Research and Quality (AHRQ) Content and Procedures Guide for the Evidence-based Practice Center Program (EPC). The [study protocol](#) was published on AHRQ's Effective Healthcare website.

2.1 Discussions With Key Informants

We recruited eight Key Informants (KIs) with different expertise, backgrounds, and professional affiliations from the following perspectives: Area Agencies on Aging, Federal agencies, home and community-based service (HCBS) providers, HCBS researchers, and beneficiary advocates. We conducted two group conferences to collect input on the Guiding Questions (GQs) and the KIs' experiences, opinions, and challenges related to HCBS, quality measures, and outcomes that are important and relevant to stakeholders, as well as gather factors involved in the decision to choose HCBS. The KIs were invited to review and provide feedback on the draft report; however, all findings and opinions expressed within the report are solely the authors.

2.2 Grey Literature Search

The grey literature search focused on GQ 2, existing HCBS quality measures and those that are under development, but the search also captured any additional published literature related to GQ 1. We searched the following sources: ClinicalTrials.gov, conference proceedings, web search engines (Google), and Federal and State Government websites, patient and industrial advocate groups, research institutions, and medical societies, and this was supplemented by additional websites and databases provided by the KIs. A Supplemental Evidence and Data for Systematic Reviews (SEADS) portal was posted from 09/28/2023 to 11/06/2023 to collect additional study-specific information from industry stakeholders, professional societies, and researchers. In addition, we sought and reviewed grey literature sources proposed by KIs. A Federal Register Notice was posted for this review. One reviewer conducted the grey literature search and tracked screening. A second reviewer reviewed and verified the eligibility of the identified literature.

2.3 Published Literature Search

We conducted a comprehensive database search, including Embase®, Epub Ahead of Print, In-Process & Other Non-Indexed Citations, MEDLINE® Daily, MEDLINE®, Cochrane Central Registrar of Controlled Trials, Ovid® Cochrane Database of Systematic Reviews, and Scopus® from January 1, 2000 to December 7, 2023. Reference mining of relevant systematic reviews/meta-analyses, eligible primary studies (i.e., randomized controlled trials [RCTs], observational studies, surveys, qualitative studies, and mixed-method studies) was conducted to identify additional literature. The literature search strategy was developed by an experienced medical librarian and peer-reviewed by an independent information specialist. The same medical librarian conducted the literature search. The detailed search strategy is listed in Appendix A

For abstract screening, we used a validated natural language processing (NLP) algorithm developed by DistillerSR® (Evidence Partners Incorporated, Ottawa,). Each abstract was screened by two independent human reviewers and the NLP technique with constant surveillance

2. Methods

of possible misclassified citations for quality control. Abstracts were advanced for full-text screening if there was consensus for inclusion or conflicts. Independent reviewers, working in pairs, screened the full-text version of eligible references. Discrepancies between the reviewers were resolved through discussions and consensus. When consensus could not be reached, a third reviewer resolved the difference.

We applied the following inclusion and exclusion criteria for the studies identified in the literature search (Table 1). We focused on studies conducted in the United States. We limited the literature to studies published in English. Studies published after the year 2000 were also excluded as the concept of person-centered HCBS only emerged in 2000s. Included systematic reviews were not limited to the older population (≥ 60 years) and included studies published prior to year 2000. For GQ 1 (HCBS effectiveness), we included RCTs, comparative observational studies, and systematic reviews/meta-analyses. For GQ 2 (HCBS quality measures), we broadly defined quality measures as tools (e.g., survey, questionnaire) that measured HCBS delivery, outcome, patient perception, organizational structure and culture, and other related factors. We focused on quality measure sets consisting of multiple domains recommended by the National Quality Forum Framework on HCBS Quality,² rather than a single-item quality measure (i.e., quality indicators [QIs]), measurement of functional or clinical outcomes (e.g., Disability Rating Scale, UCLA Loneliness Scale), or quality-of-life (QoL) scales (e.g., Quality of Life in Alzheimer's Disease Scale, Lehman Quality of Life Interview, Money Follows the Person Quality of Life Survey). For GQ 2 (HCBS quality measures) and GQ 3 (evidence gaps), we also included narrative reviews, surveys, qualitative studies, and mixed-method studies.

Table 1. PICOTS (Populations, Interventions, Comparators, Outcomes, Timing, and Settings)

PICOTS Elements	Inclusion Criteria	Exclusion Criteria
Population	<ul style="list-style-type: none"> Adults aged 60 years or older with a functional limitation, requiring assistance with activities of daily living, regardless of payer source 	<ul style="list-style-type: none"> Children Adults without disabilities Adults aged <60 years, exclusively
Interventions	<ul style="list-style-type: none"> Person-centered HCBS 	<ul style="list-style-type: none"> None
Comparators	<ul style="list-style-type: none"> Institutional care (nursing care, long-term care) without HCBS No HCBS while living in the home or community 	<ul style="list-style-type: none"> None
Outcomes	<ul style="list-style-type: none"> Mortality Time to nursing home placement Satisfaction with HCBS services Person-centered outcomes (e.g., autonomy, choice making, participating meaningful activity), Hospitalization, rehospitalization Clinical outcomes (falls, disease-related outcomes) Social isolation Quality of life (see NQF HCBS Quality Domains Report) Harms of the intervention 	<ul style="list-style-type: none"> None
Timing	<ul style="list-style-type: none"> All 	<ul style="list-style-type: none"> None

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PICOTS Elements	Inclusion Criteria	Exclusion Criteria
Settings	<ul style="list-style-type: none"> • Home settings • Independent living • Assisted living • Studies conducted in the United States 	<ul style="list-style-type: none"> • Institutional care setting, e.g., <ul style="list-style-type: none"> ○ Nursing home ○ Hospital
Subgroup Analysis	<ul style="list-style-type: none"> • Geography • Race/ethnicity • Sex • Comorbidities • Social situations (community, home) • Clinical needs (includes activities of daily living as well as other needs to care for a person) 	<ul style="list-style-type: none"> • None
Study Design	<ul style="list-style-type: none"> • GQ 1: <ul style="list-style-type: none"> ○ RCTs ○ Comparative observational studies ○ Systematic reviews or meta-analyses • GQ 2 and 3: <ul style="list-style-type: none"> ○ RCTs ○ Comparative observational studies ○ Surveys ○ Qualitative studies ○ Mixed-method studies ○ Narrative reviews ○ Systematic review or meta-analysis 	<ul style="list-style-type: none"> • In vitro studies • Erratum • Editorials • Letters • Case reports/series
Publications	<ul style="list-style-type: none"> • Studies published in English as peer reviewed full-text articles • Studies published after Year 2000 • Studies conducted in the United States 	<ul style="list-style-type: none"> • Non-English language studies • Conference abstracts

Abbreviations: HCBS = home and community-based services; GQ = Guiding Question; NQF = National Quality Forum; RCT = randomized controlled trials

2.4 Data Organization and Presentation

2.4.1 Information Management

For GQ 1 (HCBS effectiveness), we developed a standardized data extraction form to extract study characteristics (e.g., author, year, study design, inclusion and exclusion criteria, patient characteristics, intervention, comparisons, outcomes, and related items for addressing GQ 1). The standardized form was tested by all study team members using randomly selected studies. We supplemented the extracted information with data derived from the KIs and grey literature. DistillerSR® was used to create data extraction forms and facilitate data extraction.

For GQ 2 (HCBS quality measures), we developed a standardized form and extracted data in Microsoft® Word. Extracted data included the name of the HCBS quality measures, original developers, objectives, quality domains, available language, validation of quality measures, and person-centeredness. To evaluate whether the included quality measures were validated, we searched related documentation/manuals and peer-reviewed publications for information related to reliability (i.e., test-retest reliability, inter-observer reliability, or internal consistency reliability) or validity (content validity, internal structure validity, criterion-related validity, or construct validity). A quality measure was deemed to be person-centered when it evaluated certain attributes of HCBS interventions: (1) process of assessment, planning, and coordination that is focused on customers' goals, needs preferences, and values; (2) degree to which they meet customers' needs and support them in achieving their goals; or (3) workforce's approach to the delivery of services that is tailored to customers' preferences and values.²

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2.4.2 Data Presentation

We summarized the main findings of each GQ in evidence tables and described them narratively. We followed an evidence map approach, which is a systematic approach for summarizing specific characteristics of a broad field that typically uses graphics and tables and examines the distribution of evidence.⁵ Additional information extracted from KIs was synthesized and presented narratively. We retained the original language of included studies as they referred to individuals receiving HCBS using different terms such as people, patients, customers, or consumers. For example, the term “patient-centered” is frequently used in the HCBS literature, while the term “person-centered” better reflects the global focus on medical and health-related social needs. We used the latter term in the narrative synthesis of this report and retained the original terms used in the published studies in the tables that describes the studies.

2.5 Peer Review and Public Commentary

Experts and stakeholders provided external peer review on of this draft report; AHRQ also provided a review of the draft report. The draft report was posted on the AHRQ Effective Health Care website for public comment from February 23, 2024, to March 22, 2024. A disposition of comments document of the peer review and public comments will be posted approximately 3 months after the final report is published.

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3.1 Summary of Discussions With Key Informants

We completed two 1-hour group conferences with eight Key Informants (KI) in October 2023. The KIs emphasized the importance of the Guiding Questions (GQs) and were generally in agreement with the proposed methods for this Technical Brief. They agreed that literature published within the last two decades and conducted in the United States would provide many meaningful information related to the GQs. Although a few studies on populations with mental or physical disabilities may have been published in 1970s, the relevance of such information to contemporary home and community-based services (HCBS) is unclear. The KIs identified some existing HCBS quality measures and quality measures that are under development. They also identified important databases and websites to search additional quality measures.

The KIs emphasized the importance of the concept of person-centeredness, person-centered planning, and self-direction in HCBS interventions. The goals of person-centered HCBS interventions should be to improve individual's quality of life and maintain independence at home and in their community. Person-centered HCBS interventions offered opportunities for shared decision making and flexibility to choose among services that give them control of their life and honor their preferences. The KIs highlighted outcomes important to an older population, including quality of life and person-centered outcomes. The KIs outlined major challenges in providing HCBS interventions and synthesizing evidence from the literature. HCBS interventions were often labeled as "person-centered" although the majority of the literature may not provide justification of this label. HCBS providers and researchers seldom provided adequate information to evaluate whether their interventions are person-centered. In the literature, "patient-centered" and "person-centered" terminologies were often used interchangeably while the distinction was critical from KIs' perspective. "Patient-centered" terminology relates to the medical literature and clinical outcomes, whereas "person-centered" is a holistic and more comprehensive terminology that is more appropriate for the context of care that is responsive to an individual's goals, concerns, and priorities. It is also difficult to categorize HCBS interventions due to a wide range of services available across providers and States. The KIs also identified factors that could affect effectiveness of HCBS interventions, including workforce, providers' built-in capabilities, funding mechanism, sustainability, quality of care, cost, geographic location implications, disparities, and safety in community (e.g., violence). The KIs who were HCBS providers and advocate representatives reported concerns about the direct care workers (DCWs) part of the workforce. With low entry-level salary and high turnover rates, there were concerns about recruitment and retention that can impact the quality and continuity of care of HCBS. KIs emphasized that most person-centered quality measures had not been independently verified by providers and researchers. It is critical that a good HCBS quality measure should focus on individual's experiences, equitable approaches, and effectiveness of the intervention.

In summary, the KIs supported the methodological approaches for this Technical Brief and provided a comprehensive perspective on HCBS interventions from an individual and provider perspective. They also provided recommendations on synthesizing and interpreting evidence. We reviewed the KIs' input and incorporated the recommendations as appropriate in this Technical Brief.

3. Findings

3.2 Results of the Published Literature Search and Grey Literature Search

3.2.1 Findings, Guiding Question 1: Describe the Available Research on the Effectiveness of Person-Centered HCBS Interventions, for Adults Aged 60 or Older With a Functional Limitation in Home and Community-Based Settings.

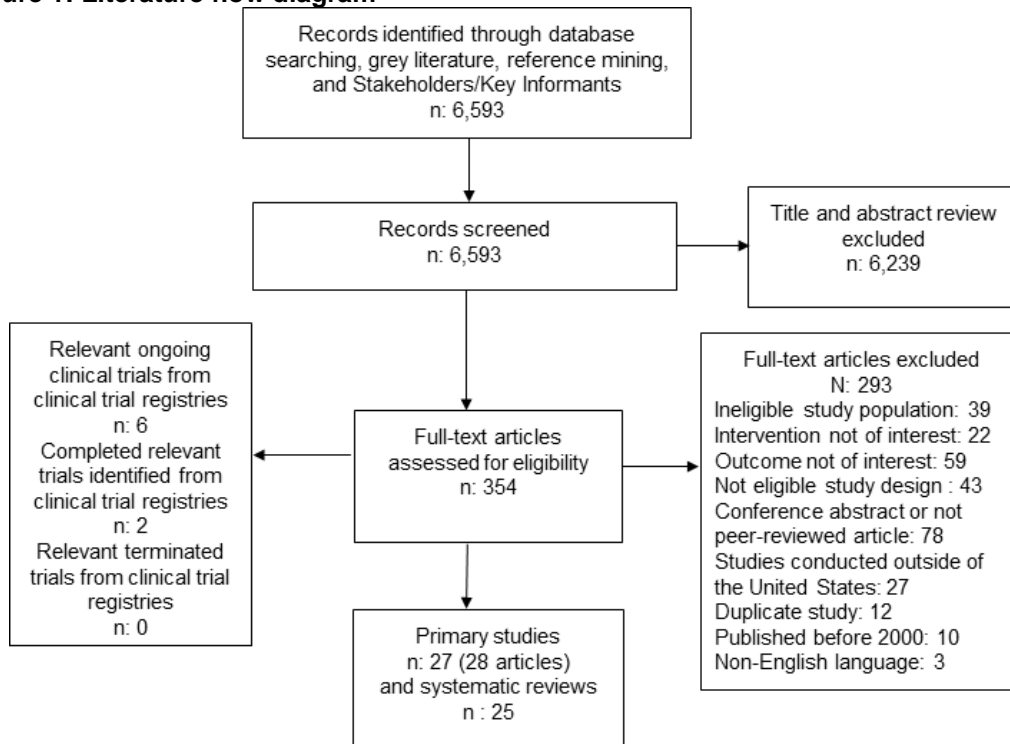
The literature search identified 6,593 citations. We excluded 6,239 articles after abstract screening. Two hundred ninety-three were excluded after full text screening. The main reasons for exclusion were not meeting inclusion criteria by the study population (n=39), intervention (n=22), outcomes (n=59), or study design (n=43), and being conference abstracts without a full-text available (n=78). The excluded studies with exclusion reasons are listed in Appendix B. Twenty-seven primary studies and 25 relevant systematic reviews met the inclusion criteria.⁶⁻⁵⁸ The results of the literature search are displayed in the flow chart in Figure 1.

Of these 27 primary studies, six were RCTs,^{6, 12, 15, 19-21, 23} eight pre/post studies,^{9, 10, 14, 18, 24-26, 28} six cross-sectional survey studies,^{16, 29, 54-56, 58} two prospective cohort studies,^{8, 13} and five retrospective cohort studies.^{7, 11, 17, 22, 27} The median age of the study population was 72.5 years old, with a range from 18 years to 97 years; 33.6% were non-White and 57.9% were female. The median followup was 12 months, ranging from 2 months to 54 months. Two studies were conducted in New England (Connecticut, Rhode Island),^{7, 8} 10 in the Middle Atlantic (Maryland, New York, Pennsylvania),^{10-14, 18, 20, 21, 26, 27} two in the Midwest (Indiana, Michigan),^{19, 22} two in the South (Missouri, Virginia),^{17, 24} six in West (California, Colorado, Hawaii, Washington State),^{6, 9, 15, 23, 25, 28, 29} and five in multiple states or unclear geographic regions.^{16, 54-56, 58} Populations studied include homebound older adults with a high risk of comorbid health conditions;^{7, 16, 17, 23} individuals with advanced dementia/Alzheimer's disease living in the community;^{10, 12, 20} people with physical disabilities, intellectual disabilities, mental health conditions, or behavioral health conditions;^{13, 14, 55, 56} those undergoing transitional periods, such as recent hospital discharges;^{8, 19, 27} community-dwelling people with high risk of functional decline;^{9, 11, 18, 21, 23-26} veteran populations;²² those with Parkinson's disease,¹⁰ a recent stroke or an advanced/terminal illnesses;^{6, 15, 19, 25, 28} and average-risk older adults living in the community to promote aging in place.^{29, 54, 58}

The included 25 relevant systematic reviews were published between 2009 and 2023.^{30-53, 57} Appendix C lists the details of these systematic reviews.

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Figure 1: Literature flow diagram



Abbreviations: n = number

3.2.1.1 Interventions

The included 27 primary studies evaluated various person-centered HCBS services, programs, or interventions for individuals with qualifying disabilities and their surrounding support systems. The details of the 27 primary studies are listed in Appendix D. Table 2 shows the evidence map of HCBS interventions by study design and population.

Interventions applied and studied include efforts toward—

- Optimizing person-centered planning^{6, 8-10, 12, 13, 15, 18, 19, 21-24, 26, 55, 58}
- Self-directed home care^{6, 8-10, 13, 15, 19, 22, 24, 26, 29}
- Unmet health related social needs^{8, 13, 24, 26, 55}
- Integrated/nonpharmacological approaches for dementia care/Alzheimer's disease^{10, 12, 20}
- Impact of physical rehabilitation on function^{10, 12, 20}
- Benefits of specific services (e.g., skilled nursing, physical therapy, occupational therapy, home health aide use, case management)^{6, 8-10, 14, 15, 17-19, 22, 24, 25, 27, 28, 54, 55}
- Collaborative care models^{6-8, 10, 13-15, 17, 18, 23, 25, 26, 28}
- Home-based palliative care programs^{6, 7, 15, 25, 28}
- Home care via telehealth^{11, 19, 23, 25}
- Implementation of geriatric resources for practical support at home and interdisciplinary care coordination surrounding high-risk transitions such as posthospital discharge periods^{8, 14, 19}

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Person-centered planning as a component of HCBS interventions was not explicitly described in 12/27 (44%) of the primary publications. Self-direction of HCBS services was not clear in 16/27 (59%) of the primary publications. Only 5/27 (19%) of the publications focused on addressing health-related social needs. An evidence map focused on these elements of person-centeredness is provided in Table 3.

Table 2: Evidence map of HCBS interventions by population*

HCBS Intervention	Population Experiencing Cognitive Impairment	Population With Functional Limitations	Population Considered High Risk and Frail	Population With Specific Advanced Disease	Immigrants	Population Experiencing Homelessness	Population With Substance Use Disorders	Veterans
Optimizing Person-Centered Planning	4	9	1	3	0	1	0	0
Integrated/ Nonpharmacological Approaches for Dementia Care/Alzheimer's Disease	3	0	0	2	0	0	0	0
Impact of Physical Rehabilitation on Function	3	0	0	2	0	0	0	0
Benefits of Specific Services (Skilled Nursing, Physical Therapy, Occupational Therapy, Home Health Aid Use, Case Management)	3	8	4	4	1	1	1	1
Collaborative Care Models	2	5	5	3	1	1	1	
Home-Based Palliative Care Programs	0	1	4	0	1	0	0	0
Home Care via Telehealth	0	4	2	1	0	0	0	0
Implementation of Geriatric Resources for Practical Support at Home and Interdisciplinary Care Coordination Surrounding High-Risk Transitions, Such as Posthospital Discharge Periods	1	2		2	0	0	1	
Self-Direction of Home Care	2	6	1	2	0	0	0	0
Addressing Unmet Health-Related Social Needs	2	3	0	0	0	0	0	0

Abbreviations: HCBS = home and community-based services

*: A study can include multiple types of HCBS interventions and multiple study population

3. Findings

Table 3: Evidence map of person-centered services in HCBS interventions

Author, Year	Person-Centered Planning	Self-Direction	Addressing Health-Related Social Needs
Kennedy-Hendricks, 2021 ¹⁴	Unclear	Unclear	No
Fabius, 2020 ⁸	Yes	Yes	Yes
Reeves, 2019 ¹⁹	Yes	Yes	No
Wang, 2019 ²⁷	Unclear	Unclear	No
Holburn, 2004 ¹³	Yes	Yes	Yes
Coppa, 2022 ⁷	Unclear	Unclear	No
Matzke, 2018 ¹⁷	Unclear	Unclear	No
Fleisher, 2018 ¹⁰	Yes	Yes	No
Sudat, 2018 ²⁵	Unclear	Unclear	No
Schubert, 2016 ²²	Yes	Yes	No
Galik, 2015 ¹²	Yes	Unclear	No
Szanton, 2015 ²⁶	Yes	Yes	Yes
Labson, 2013 ^{6, 15}	Yes	Yes	No
Resnick, 2011 ²¹	Yes	Unclear	No
Raven, 2011 ¹⁸	Yes	Unclear	No
Stark, 2009 ²⁴	Yes	Yes	Yes
Fisher, 2007 ⁹	Yes	Yes	No
Sommers, 2000 ²³	Yes	Unclear	No
Reisberg, 2017 ²⁰	Unclear	Unclear	No
Liang, 2017 ¹⁶	Unclear	Unclear	No
Foltz, 2014 ¹¹	Unclear	Unclear	No
Fernandes, 2010 ²⁸	Unclear	Unclear	No
Wiener, 2007 ²⁹	Unclear	Yes	No
Chong, 2022 ⁵⁴	Unclear	Unclear	No
Stancliffe, 2009 ⁵⁶	Unclear	Unclear	No
Isvan, 2023 ⁵⁵	Yes	Unclear	Yes
Chong, 2024 ⁵⁸	Yes	Yes	Yes

Abbreviations: HCBS = home and community-based services

3. Findings

We identified 25 relevant systematic reviews. Some systematic reviews evaluated specific HCBS components, including case management,^{30, 39, 47} person-centered planning,⁴⁹ and patient support programs.⁴⁶ The other systematic reviews covered a wide range of HCBS interventions.^{30, 33, 35, 36, 38, 39, 43, 47, 50-52, 57} A few systematic reviews included meta-analyses. Cochrane et al. compared reablement (i.e. restorative care) with usual care and found reablement might be slightly more effective than usual care in improving function with no significant difference in mortality or unplanned hospital admission.³³ A systematic review of 33 RCTs showed that person-centered care, communication skills training, and adapted dementia care mapping for patients with dementia significantly reduced symptomatic and severe agitation immediately or after six months of implementation,⁴⁴ while another systematic review found no difference between usual care and patient-level interventions, interventions tailored to recipients' skills and/or interests, or caregiver-level interventions for managing agitation/aggression in people with dementia.³² A meta-analysis of 41 studies found that home dialysis was associated with better physical quality-of-life (QoL) scores and no difference on mental QoL scores compared with in-clinic dialysis.³¹

3.2.1.2 Populations

The populations studied in primary studies and systematic reviews can be generally categorized to those with functional disability, cognitive impairment, high risk/frail conditions, and disease-specific conditions.

Cognitive impairment conditions included studies evaluating people with intellectual disabilities, those living with early dementia in an assisted living setting, those with Alzheimer's disease and other dementias with behavioral manifestations, and people needing psychiatric services for various behavioral and mental health conditions.^{10, 12-14, 20, 29, 32, 40, 41, 44, 45, 49, 55, 56}

Populations with functional limitations included older adults with physical disabilities who receive interventions to improve daily activity performance, those undergoing nursing home transitions, those who were recent hospital discharges, and those in transitional care for behavioral health needs.^{8, 9, 11, 18, 19, 21, 23-27, 29, 54, 58}

High-risk and frail conditions included people with serious illness requiring palliative care services, individuals with multiple illnesses requiring interdisciplinary chronic disease management, older adults who were at high risk of rehospitalization, frail, older adults living in the community, and chronically ill seniors with life-limiting illnesses.^{6, 7, 15-17, 23, 25, 28, 34, 36, 38}

Specific advanced disease conditions requiring more in-home assistance included studies evaluating people with Parkinson's disease and related movement disorders, Alzheimer's disease and other dementias, those with poststroke conditions, and dialysis patients.^{10, 14, 18-20, 31, 37, 52, 53}

In one study, a majority of the studied population (97.8%) were low-income immigrants from Asia and the Pacific Islands.²⁸ Individuals with substance use disorders and those experiencing homelessness were reported in two studies, although their results were not reported separately, and the impact of these circumstances was not further addressed via analysis or specific HCBS intervention modifications.^{14, 18}

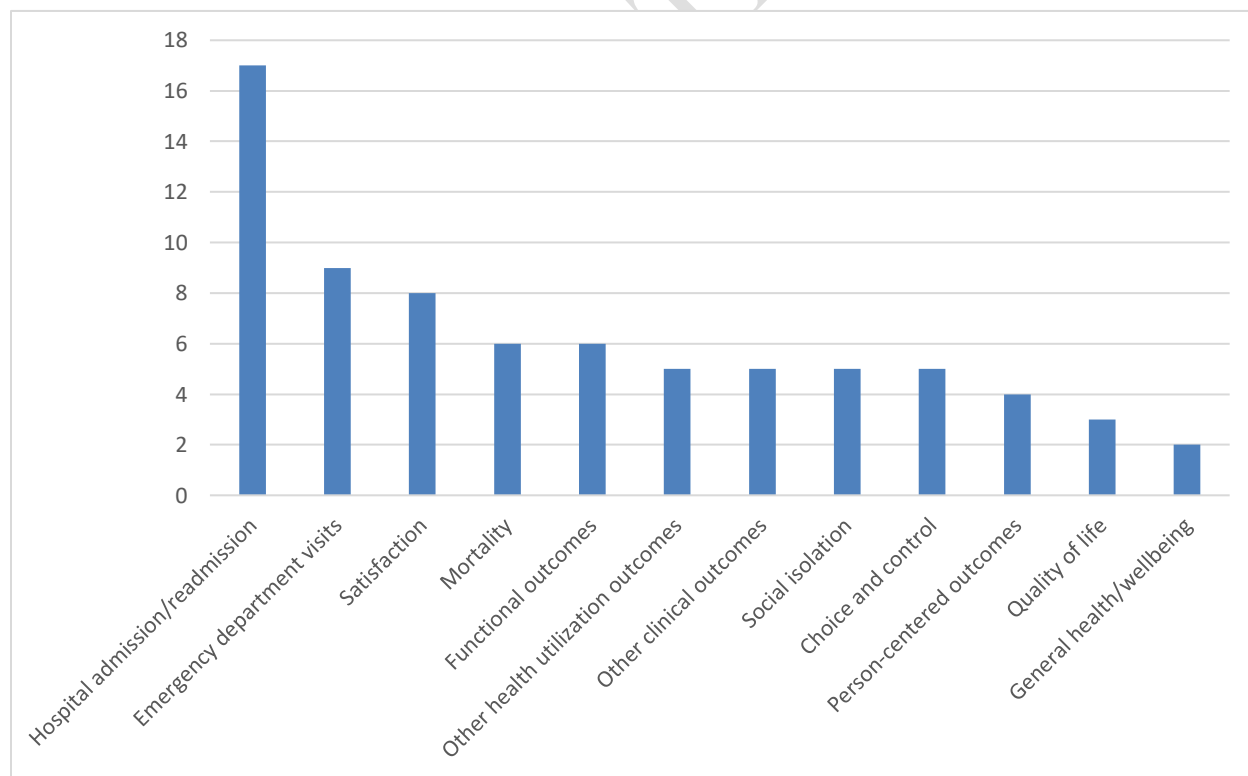
One study specifically addressed the veteran population.²² The collaborative models included various healthcare professionals, including physicians, nurses, pharmacists, DCW, and case managers.^{17, 18, 22, 24} Only three primary studies^{8, 12, 29} and one systematic review evaluated DCW in HCBS interventions.⁵⁷

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3.2.1.3 Primary Outcomes

Seventeen of the included 27 primary studies reported hospital admission/readmission, though various definitions were used (e.g., number of hospital admission per year, number of patients with 30-day readmissions, number of inpatient days).^{6-8, 10-12, 14, 15, 17-19, 21-23, 25, 27, 28, 54} Nine studies reported emergency department visits.^{6, 7, 10, 11, 15, 18, 21, 22, 25, 28} Other health utilization outcomes included community living from institutional living,¹³ hospice enrollment,²⁵ use of preventive care (e.g., blood pressure check, cholesterol check, routine checkup),¹⁶ implementation of advanced directive planning,²⁸ adoption of do-not-resuscitate orders,²⁸ physical exam, wellness visit, and dental visit.⁵⁴ Six studies reported mortality,^{6, 7, 15, 21, 23, 25, 28} two reported falls and injuries,^{12, 21} five reported other clinical outcomes (e.g., disease recurrence, PHQ-9 depression score, systolic/diastolic blood pressure),^{17, 19, 20, 26, 28} and six reported functional outcomes (e.g., activities of daily living/instrumental activities of daily living, physical activities, walking distance).^{9, 13, 19-21, 26} Other outcomes reported included quality of life in three studies,^{19, 23, 28} overall wellbeing/health in two studies,^{55, 56} satisfaction in eight studies,^{13, 15, 24, 29, 54-56, 58} choice and control outcome (i.e., choice and control in daily activities) in five studies,^{8, 13, 54, 55, 58} and social isolation in five studies (i.e., able to see or talk to friends and family).^{13, 54-56, 58} Figure 2 shows the distribution of primary studies by outcomes. To provide a more comprehensive summary, we considered HCBS outcomes from all sources, including primary studies, systematic reviews, and KI input, and categorized as depicted in Figure 3.

Figure 2: Number of primary studies by outcome



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Figure 3: Categories of HCBS outcomes derived from individual studies, systematic reviews, and KI feedback

Clinical Outcomes
• Mortality, falls, injuries, disease recurrence, A1c, lipid fractions, blood pressure, PHQ-9, dementia related agitation
Functional Outcomes
• ADLs/IADLs, physical activity, walking distance
Quality of life/well-being
• Quality of life scales, self-reported overall health/well-being
Choice and control
• Choice and control of plan of care and daily activities
Social isolation
• Ability to see or talk to friends and family
Utilization Outcomes
• Hospitalization, readmission, nursing home admission, ED visits, wellness visits, use of preventive care, hospice enrollment, adherence
Economic outcomes
• Incremental cost, cost-effectiveness
Satisfaction
• Satisfaction with care
Other outcomes
• Legal problems, legal assistance

Abbreviations: ADL = activities of daily living; ED = Emergency Department; HCBS = home and community-based services; KI = Key Informant; IADL = instrumental activity of daily living; PHQ-9 = Patient Health Questionnaire-9

3.2.1.4 Effect Modifiers

Six primary studies evaluated and reported effect modifiers of HCBS interventions.^{16, 19, 23, 27, 29, 56} Two RCTs found higher intensity of HCBS interventions (e.g., nurse/social worker contacts, skilled nursing/physical therapy) was associated with better outcomes, including fewer hospital admissions, fewer physician visits, and better social activities.^{16, 23} One RCT evaluating home-based social worker-led case management versus usual care reported no significant difference on participants' age, disease severity, discharge destination, or caregiver's participation.¹⁹ A cross-sectional survey study of older adults with at least one chronic condition found that receiving preventive services was higher in males, those who were older, those who were married, those with higher education, those with higher household income, those with a managed care plan, and those with Medicare plus private insurance.¹⁶ Another cross-sectional survey of adults with physical disabilities, intellectual disabilities, or developmental disabilities found that being female, being older, and having no limitation of activities of daily living/instrumental activities of daily living were associated with higher satisfaction of HCBS intervention.²⁹ Stancliffe et al. surveyed 1,885 adults with intellectual and developmental disabilities and found being less lonely was associated with smaller settings, living with family, and choosing living companions.⁵⁶

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Multiple systematic reviews evaluated HCBS facilitators and barriers that might improve HCBS implementation.^{34-36, 42-45, 48, 50} The following factors were identified:

- Knowledge, skills, and related education/training of caregivers and providers^{34, 35, 42, 43, 50}
- Communication and relationship building^{35, 42, 44, 45, 48, 50}
- Person-centeredness of the intervention^{36, 41-45, 48-50, 55}
- Multidisciplinary teamwork and coordinated care^{36, 42, 43, 50}
- Autonomy of older people and independence^{42, 43, 50}
- Providers' organizational process and culture^{35, 36, 42, 43, 48, 50}

3.2.1.5 Study Designs

The 27 primary studies included numerous study designs to evaluate the effectiveness of HCBS interventions. There were six RCTs,^{6, 12, 15, 19-21, 23} eight pre/post studies,^{9, 10, 14, 18, 24-26, 28} six cross-sectional survey studies,^{16, 29, 54-56, 58} two prospective cohort studies,^{8, 13} and five retrospective cohort studies.^{7, 11, 17, 22, 27}

Study designs included in the 25 systematic reviews³⁰⁻⁵³ were qualitative studies, RCTs, cross-sectional studies, pre/post studies, prospective cohort studies, retrospective cohort studies, and mixed methods studies. The number of studies by study designs are displayed in Table 4.

Table 4: Number of studies by study designs*

Study Design	Population Experiencing Cognitive Impairment	Populations With Functional Limitations	Population Considered High Risk and Frail	Population With Specific Advanced Disease	Immigrants	Population Experiencing Homelessness	Population With Substance Use Disorders	Veterans
RCT	2	3	2	2	0	0	0	0
Pre/Post Studies	2	5	2	3	1	1	1	0
Cross-Sectional Surveys	3	3	1	0	0	0	0	0
Prospective Cohort Studies	1	1	0	0	0	0	0	0
Retrospective Cohort Studies	0	2	2	0	0	0	0	1

Abbreviations: RCT = randomized controlled trial

*: A study can include multiple types of HCBS interventions and multiple study populations

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3.2.2 Findings, Guiding Question 2: What Quality Measures Related To Person-Centered HCBS Interventions Exist or Are Under Development?

3.2.2.1 Existing Quality Measures

Using a broad definition of a quality measure to include measure sets, surveys, and questionnaires, the grey and published literature search and KI feedback identified 29 existing quality measures related to HCBS interventions (Table 5). These quality measures apply to a broad range of HCBS interventions and populations without restricting to specific types of interventions or specific disabilities. A few quality measures were developed for a specific geographic location (e.g., a specific State program). These quality measures were developed to benchmark HCBS performance at State, agency, or provider level. Most of the quality measure information were collected through survey questionnaires by telephone or in-person interviews. A wide range of quality domains were covered in these quality measures (presented in Table 5). These domains converge into 13 unique categories derived from the revised National Quality Forum Framework on HCBS Quality by the Rehabilitation Research and Training Center on HCBS Outcome Measures (RTCOTM) at the University of Minnesota and include 11 domains from the original National Quality Forum Framework on HCBS Quality.^{2, 59} These domains are summarized below:

- Service delivery and effectiveness
- Person-centered planning and coordination
- Choice and control
- Community inclusion
- Caregiver support
- Workforce
- Human and legal rights
- Equity
- Holistic health and functioning
- System performance and accountability
- Consumer leading in system development
- Fluctuation of need*
- Level of caregiver well-being*

*: Added two domains from the original National Quality Forum Framework on HCBS Quality

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Table 5: List of existing quality measures related to person-centered HCBS

Name of Measure	Developer	Target Population	Objectives	Domains
HCBS Quality Measure Set	Centers for Medicare & Medicaid Services ⁶⁰	Medicaid beneficiaries	A set of nationally standardized quality measures for Medicaid-funded HCBS to promote common and consistent use of quality measures and have comparative quality data on HCBS programs.	<p>3 HCBS quality priority areas and 5 meaningful measures domains</p> <p>Quality priority areas:</p> <ul style="list-style-type: none"> • Access • Rebalancing • Community integration <p>Meaningful measures domains:</p> <ul style="list-style-type: none"> • Promote effective communication and coordination of care • Promote effective prevention and treatment of chronic disease • Work with communities to promote best practices of healthy living • Make care affordable • Strengthen person and family engagement as partners in their care <p>Person-centeredness: Yes Validated: Yes English versions available A compilation of existing quality measures</p>
The HCBS Consumer Assessment of Healthcare Providers and Systems (CAHPS) Home and Community-Based Services Survey 1.0	Centers for Medicare & Medicaid Services ⁶¹	Older adults, people with physical disabilities, intellectual or developmental disabilities, acquired brain injury, and with mental health or substance use disorders	Cross-disability survey for adults receiving long-term services to measure experience with Medicaid HCBS delivered by providers.	<p>69 Core items:</p> <ul style="list-style-type: none"> • Getting needed services • Communication with providers • Case managers • Choice of services • Medical transportation • Personal safety • Community inclusion and empowerment <p>Person-centeredness: Yes Validated: Yes English and Spanish versions available</p>

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Name of Measure	Developer	Target Population	Objectives	Domains
Person-Centered Outcome Measures	National Committee for Quality Assurance (NCQA), the John A. Hartford Foundation, the SCAN Foundation ⁶²	People with complex health status and their care partners	The measures work in tandem with clinical care to help people living with complex health needs make progress toward a health outcome goal that matters to them	<p>There sets of measures:</p> <ul style="list-style-type: none"> • Measure 1: Goal Identification • Measure 2: Goal Follow-up • Measure 3: Goal Achievement <p>Person-centeredness: Yes English version available</p>
The National Core Indicators for Intellectual and Developmental Disabilities (NCI-ID)	Human Services Research Institute and National Association of States United for Aging and Disabilities ⁶³	People with intellectual and developmental disabilities	A survey instrument to help the National Association of State Directors of Developmental Disabilities Services (NASDDDS) member agencies to benchmark performance over time, across states, and establish national benchmarks for community living.	<p>4 Domains and 22 sub-domains:</p> <ul style="list-style-type: none"> • Individual outcomes • System performance • Health, wellness, and rights • Family experience <p>Person-centeredness: Yes English and Spanish version available</p>

3. Findings

Name of Measure	Developer	Target Population	Objectives	Domains
National Core Indicators for Aging and Disabilities (NCI-AD)	Human Services Research Institute and National Association of States United for Aging and Disabilities ⁶⁴	Older adults; people with physical disabilities	A survey instrument to help states assess performance over time, across states, and establish national benchmarks for community living.	<p>19 Domains with over 80 indicators:</p> <ul style="list-style-type: none"> • Community participation • Access to community • Work • Everyday living • Relationship • Safety • Satisfaction • Service coordination • Rights and respect • Care coordination • Access to technology • Access to needed equipment • Healthcare • Medications • Wellness • Affordability • Choice and control • Self-direction • Person-centered planning <p>Person-centeredness: Yes Validated: Yes English, Spanish, Hmong, Russian, and Somali version available</p>
Personal Outcome Measures (POM)	Council on Quality and Leadership ⁶⁵	Older adults, and people with intellectual and developmental disability, or mental health challenges	A survey tool to explore quality-of-life outcomes for person receiving person-centered care.	<p>HCBS-related quality measures:</p> <ul style="list-style-type: none"> • Personal goals • Services choice • Abuse and neglect • Health • Integrated environments • Interaction with the community • Participation in the community <p>Person-centeredness: Yes Validated: Yes English version available</p>

3. Findings

Name of Measure	Developer	Target Population	Objectives	Domains
Quality Measures for Managed LTSS	Centers for Medicare & Medicaid Services ⁶⁶	Older adults, people with physical disabilities, intellectual or developmental disabilities, acquired brain injury, and mental health or substance use disorders or both, who are in the Managed Long-Term Services and Supports (MLTSS) programs	A set of quality measures to help states evaluate MLTSS programs	<p>Assessment and Care Planning:</p> <ul style="list-style-type: none"> • Long-Term Services and Supports Comprehensive Assessment and Update (MLTSS-1) • Long-Term Services and Supports Comprehensive Care Plan and Update (MLTSS-2) • Long-Term Services and Supports Shared Care Plan with Primary Care Provider (MLTSS-3) • Long-Term Services and Supports Reassessment/Care Plan Update after Inpatient Discharge (MLTSS-4) • Screening, Risk Assessment, and Plan of Care to Prevent Future Falls (MLTSS-5) <p>Rebalancing Long-Term Services and Supports:</p> <ul style="list-style-type: none"> • Long-Term Services and Supports Admission to a Facility from the Community (MLTSS-6) • Long-Term Services and Supports Minimizing Facility Length of Stay (MLTSS-7) • Long-Term Services and Supports Successful Transition after Long-Term Facility Stay (MLTSS-8) <p>Person-centeredness: Yes Validated: Yes English versions available</p>

3. Findings

Name of Measure	Developer	Target Population	Objectives	Domains
Quality Measure for Community-Based Services and Supports in Medicaid Managed Long Term Care	New York State ⁶⁷	Medicaid beneficiaries in the Managed Long Term Care program in New York State	Quality measures to improve incentives and oversight of the Managed Long Term Care program in New York to ensure access to community-based services	<p>Medical measures:</p> <ul style="list-style-type: none"> • Skin breakdown/ decubitus condition • Falls • Other accidents • Independence and functional level • Social measures: • No formal measures were given, though those measures were “pertaining to positive social outcomes.” <p>Examples include:</p> <ul style="list-style-type: none"> • Satisfaction with one’s ability to participate in the community • Number of enrollees who are employed • Number of enrollees pursuing higher education <p>Person-centeredness: Yes English versions available</p>

3. Findings

Name of Measure	Developer	Target Population	Objectives	Domains
Environmental Scan of Measures for Medicaid Title XIX Home and Community-Based Services Measure Scan	Agency for Healthcare Research and Quality ⁶⁸	Medicaid beneficiaries	An environmental scan of existing and potential HCBS quality measures for the Medicaid program as of July 5, 2007	<p>21 quality measures related to three domains:</p> <p>Client Functioning:</p> <ul style="list-style-type: none"> • Change in daily activity function • Availability of support with everyday activities when needed. • Presence of friendships • Maintenance of family relationships • Employment status • School attendance (children only) • Community integration • Receipt of recommended preventive healthcare services • Serious reportable adverse health events • Avoidable hospitalizations <p>Client Experience:</p> <ul style="list-style-type: none"> • Respectful treatment by direct service providers • Opportunities to make choices about providers • Opportunities to make choices about services • Satisfaction with case management services • Client perception of quality of care • Satisfaction and choice regarding residential setting • Client report of abuse and neglect • Availability of support for resilience and recovery (mental health service recipients only) <p>Program Performance:</p> <ul style="list-style-type: none"> • Access to case management services • Availability of care coordination • Receipt of all services in the care plan <p>Person-centeredness: Yes English versions available</p>

3. Findings

Name of Measure	Developer	Target Population	Objectives	Domains
Quality Indicators for the Home and Community-Based Services Population	Schultz et al., 2012 ⁶⁹	Medicaid beneficiaries	Quality indicators to measure health and well-being of Medicaid beneficiaries, with focus on preventable hospitalization	<p>Three composite measures from AHRQ</p> <ul style="list-style-type: none"> • PQIs and two individual measures • ACSC Chronic Conditions • ACSC Acute Conditions • ACSC Overall Conditions • Pressure ulcers • Injurious falls <p>Person-centeredness: No Validated: Yes English versions available</p>
HCBS Composite Measures	Mathematica Policy Research ⁷⁰	General population	Risk-adjusted HCBS composite measures to help State benchmark HCBS Populations.	<p>Based on AHRQ's HCBS quality indicators,⁶⁹ the authors developed risk-adjusted measures for three quality measures:</p> <ul style="list-style-type: none"> • Pressure ulcer • ACSC Chronic Conditions • ACSC Acute Conditions <p>Person-centeredness: No English versions available</p>
Managed Long Term Care Partial Subpopulation Value Based Payment Quality Measure Set	New York State Department of Health ⁷¹	Medicaid beneficiaries in New York's Managed Long Term Care program	Quality measures to be used in value-based payment for New York's Managed Long Term Care program	<p>Approved quality measures:</p> <ul style="list-style-type: none"> • Emergency room visit • Falls resulting in medical intervention • Falls that resulted in major or minor injury • Influenza vaccination • Remained stable or demonstrated improvement in pain intensity • Remained stable or demonstrated improvement in NFLOC score • Remained stable or demonstrated improvement in urinary continence • Remained stable or demonstrated improvement in shortness of breath • Uncontrolled pain • PAH for a primary diagnosis of heart failure, respiratory infection, electrolyte imbalance, sepsis, anemia, or urinary tract infection <p>Person-centeredness: Yes English versions available</p>

3. Findings

Name of Measure	Developer	Target Population	Objectives	Domains
Long-Term Services and Supports State Scorecard	AARP Public Policy Institute, the Commonwealth Fund, the John A. Hartford Foundation, and the SCAN Foundation ⁷²	Older adults, people with physical disabilities, and family caregivers	The Scorecard to benchmark the performance of State LTSS	<p>The Scorecard measures 5 dimensions with 50 quality indicators:</p> <ul style="list-style-type: none"> • Affordability and access • Choice of setting and provider • Safety and quality • Support for family caregivers • Community integration <p>Person-centeredness: Yes English versions available</p>
Long-Term Services and Supports Distinction for Health Plans standards	National Committee for Quality Assurance (NCQA) ⁷³	People receiving managed LTSS	The NCQA's Distinction survey to provide a framework for organizations to deliver efficient, effective, and person-centered LTSS	<p>The survey focuses on five areas:</p> <ul style="list-style-type: none"> • Person-centered care planning • Care transitions • Coordination of services • Critical incident management system • Qualifications and assistance for LTSS Providers <p>Person-centeredness: Yes English versions available</p>
Conceptual Framework for Quality and Outcome Measurement in Long-Term Services and Supports	Community Living Policy Center ⁷⁴	People receiving LTSS	A conceptual framework for LTSS quality improvement	<p>Quality domains include:</p> <ul style="list-style-type: none"> • Program characteristics • System responsiveness • Paid and unpaid providers • Supportive environment • LTSS received • Consumer outcomes <p>Person-centeredness: Yes English versions available</p>

3. Findings

Name of Measure	Developer	Target Population	Objectives	Domains
Person-Centered Practices In Assisted Living	UNC-CEAL Collaborative ⁷⁵	People living in Assisted Living settings	A questionnaire developed to benchmark and monitor person-centered practices in assisted living and similar long-term care settings	<p>Nine domains included:</p> <ul style="list-style-type: none"> • Core values and philosophy • Relationships and community • Senior management/ownership/governance • Leadership • Workforce • Services • Meaningful life • Environment • Accountability <p>Person-centeredness: Yes Validated: Yes English versions available</p>
Home-Based Palliative Care Services for Underserved Populations	Fernandes, et al. ²⁸	Low-income, immigrants from Asia and the Pacific Islands with palliative care	A prospective study to evaluate quality of home-based palliative care in Hawaii	<p>Outcomes/quality evaluated:</p> <ul style="list-style-type: none"> • Symptom relief • Quality of life • Use of community resources • Hospitalization and emergency department visits • Advance care planning • Satisfaction with home based palliative care <p>Person-centeredness: No English versions available</p>

3. Findings

Name of Measure	Developer	Target Population	Objectives	Domains
Services Selected Inventory of Quality-of-Life Measures for LTSS Participant Experience Surveys	University of California, San Francisco Center for Personal Assistance ⁷⁶	People receiving LTSS	A survey focusing on community integration	<p>Measures included:</p> <ul style="list-style-type: none"> • Satisfaction with living arrangement • Control over transportation and leaving the house • Control over leisure activities • Control over other daily activities • Satisfaction with amount of social contact • Satisfaction with extent of social network • Satisfaction with use of time • Satisfaction with level of activity • Roles, fulfillment, meaning • Satisfaction with extent of participation • Quality or nature of participation • Membership in community <p>Person-centeredness: Yes English versions available A compilation of existing quality measures</p>
Measurement Opportunities and Gaps	Long-Term Quality Alliance ⁷⁷	People receiving transitional care in LTSS	Quality measures for LTSS beneficiaries for measure development and research	<p>Three domains with 12 recommended quality measures:</p> <ul style="list-style-type: none"> • Person/family-centered care • Transitional care processes • Performance outcomes <p>Person-centeredness: Yes English versions available</p>
Participant Experience Surveys Elderly and Disabled	MEDSTAT Group ⁷⁸	Adults with physical disabilities	In-person interview questionnaire	<p>4 domains with 33 indicators:</p> <ul style="list-style-type: none"> • Access to Care • Choice and control • Respect/dignity • Community integration/inclusion <p>Person-centeredness: Yes English versions available</p>

3. Findings

Name of Measure	Developer	Target Population	Objectives	Domains
Participant Experience Survey Mental Retardation/Developmental Disabilities	MEDSTAT Group ⁷⁹	People with intellectual and developmental disabilities	In-person interview questionnaire to monitor quality	<p>4 domains with 51 indicators:</p> <ul style="list-style-type: none"> • Access to care • Choice and control • Respect/dignity • Community integration/inclusion <p>Person-centeredness: Yes English versions available</p>
Personal Experience Outcomes Integrated Interview and Evaluation System	University of Wisconsin-Madison ⁸⁰	Adults with physical disabilities in community-based LTSS	In-person interview questionnaire to measure person-centered quality of life	<p>149 items covering the following domains:</p> <ul style="list-style-type: none"> • Choice and control • Community inclusion • Equity • Holistic health and functioning • Human and legal rights • Person-centered planning and coordination • Service delivery and effectiveness • Workforce <p>Person-centeredness: Yes English versions available</p>
The Invisible Homebound Setting Quality-of-Care Standards for Home-Based Primary and Palliative Care	Leff and Ritchie ⁸¹	Patients for home-based primary and palliative care	Quality of care framework with domains, standards, and quality indicators	<p>10 Domains with 20 quality indicators:</p> <ul style="list-style-type: none"> • Assessment • Care coordination • Safety • Quality of life • Provider competency • Goal attainment • Education • Access • Patient and caregiver experience • Cost or affordable care <p>Person-centeredness: Yes English versions available</p>

3. Findings

Name of Measure	Developer	Target Population	Objectives	Domains
interRAI Home Care Quality Indicators	interRAI ⁸²	General population	Risk-adjusted quality indicators to evaluate home-care service agencies	<p>20 quality indicators covering the following domains:</p> <ul style="list-style-type: none"> • Nutrition • Medication • Incontinence • Ulcers • physical function • cognitive function • pain • Safety/environment <p>English versions available</p>
Satisfaction With Paid Personal Assistance Scale	Wiener, et al. ²⁹	Medicaid beneficiaries receiving HCBS	An 8-item Satisfaction With Paid Personal Assistance Scale was developed to evaluate consumer-directed vs agency-directed home care in Washington State.	<p>The 8-item survey questionnaire includes:</p> <ul style="list-style-type: none"> • How happy overall with the paid care received? • Has it ever been difficult to get problems resolved or fixed? • How well get along with paid helper? • Any trouble communicating with paid helper? • Problems of paid helper ignoring survey participant? • Problems with paid helper treating survey participant badly? • Is paid helper competent and well trained? • Is paid helper respectful? <p>Person-centeredness: No English versions available</p>

3. Findings

Name of Measure	Developer	Target Population	Objectives	Domains
Bundling, Benchmarking, and Beyond: Paying for Value in Home- and Community-Based Services	Bennet, et al. ⁸³	Medicaid beneficiaries primarily on HCBS in the context of LTSS	A report provided recommendations of HCBS quality measures for State policymakers	<p>To select quality measures, the following questions should be considered:</p> <ul style="list-style-type: none"> • Which stakeholders should be involved in defining high-quality HCBS (e.g., beneficiaries, families, providers)? • What types of metrics are important to consider for HCBS, based on agreed-on definitions of high-quality HCBS (e.g., clinical measures, beneficiaries' satisfaction, quality of life)? • Which measures will address individual, provider, MCO, and HCBS program-level quality? • Which metrics have available data sources or require original data collection using survey instruments or other tools? • Which HCBS experts could help review candidate quality measures? <p>Person-centeredness: Yes English versions available</p>
Oregon HCBS Individual Experience Survey	Oregon Health Authority ⁸⁴	Older adults, and adults with physical disabilities	A survey to evaluate consumer satisfaction with HCBS and HCBS quality	<p>The 73-question survey covering the following domains:</p> <ul style="list-style-type: none"> • Choice and Control • Community Inclusion • Human and Legal Rights • Service Delivery and Effectiveness <p>Person-centeredness: Yes English versions available</p>

3. Findings

Name of Measure	Developer	Target Population	Objectives	Domains
RTCOM HCBS Outcome Measures	University of Minnesota ⁸⁵	Older adults, and adults with intellectual/developmental, physical, age-related, or psychiatric disabilities and traumatic/acquired brain injury	A set of two-tiered measures to evaluate HCBS outcomes	<p>8 domains:</p> <ul style="list-style-type: none"> • Choice and control domain measures • Consumer leadership in system • Development measures • Freedom from abuse and neglect domain measure • Employment measures • Person-centered planning and coordination domain measures • Meaningful community-based activity • Social connectedness • Transportation <p>Person-centeredness: Yes English versions available</p>
The Home Dialysis Care Experience (Home-DCE) instrument	Rivara ⁸⁶	Patients with kidney failure undergoing home dialysis	A patient-reported experience measure for patients undergoing home dialysis	<p>26 items covering the following 6 areas:</p> <ul style="list-style-type: none"> • Communication and education of patients • Concern and helpfulness of the care team • Proficiency of the care team • Patient-centered care • Care coordination • Amenities and environment <p>Person-centeredness: Yes Validated: Yes English and Spanish versions available</p>

Abbreviations: ACSC = Ambulatory Care Sensitive Condition; AHRQ = Agency for Healthcare Research and Quality; CAHPS = Consumer Assessment of Healthcare Providers and Systems; Home DCE = Home Dialysis Care Experience, HCBS: home and community-based services; LTSS = long-term services and supports; MCO = managed care organizations; MLTSS = Managed Long-Term Services and Supports; NASDDDS = National Association of State Directors of Developmental Disabilities Services; NCI-AD = National Core Indicators for Aging and Disabilities; NCI-IDD = National Core Indicators for Intellectual and Developmental Disabilities; NCQA = National Committee for Quality Assurance; NFLOC = Nursing Facility Level of Care; PAH = potentially avoidable hospitalizations; POM = Personal Outcome Measures; PQI = Prevention Quality Indicators; RTCOM = Research and Training Center on HCBS Outcome Measurement; UNC-CEAL = University of North Carolina-Center for Excellence in Assisted Living

Domains presented in Table 5 were presented by the quality measures originally. However, these domains can generally be categorized by the revised National Quality Forum Framework on HCBS Quality.

3. Findings

3.2.2.2 Quality Measures Under-Development

Through KI discussions and grey literature search, we identified three sets of person-centered HCBS quality measures that are currently under development.

- Shirley Ryan AbilityLab RRTC HCBS outcomes
- HCBS outcomes by the National Quality Forum and the California Community Living Network
- The Lewin Group, the National Committee for Quality Assurance, Qlarant, George Washington University and DMA Health Strategies

These quality measures under development intend to improve measurement of person-centered outcomes, which are often more difficult to quantify because this involves measuring the degree of control individuals have over services, including the amount, duration, scope as well as choice. These measures take a more holistic look beyond medical needs and considers what individuals are most comfortable with, factoring in current abilities and other social, emotional, and spiritual needs. These quality measures also involve more shared decision making to make sure that physical and emotional well-being are top priorities.

3.2.3 Findings, Guiding Question 3: Describe the Gaps that Exist in the Current Research

3.2.3.1 Gaps in Person-Centered HCBS Interventions

In a multi-component, complex intervention framework, DCWs are considered a component of the intervention. We identified literature describing high DCW turnover and attrition and training concerns,⁸⁷ consistent with feedback from the KIs; however, without studies evaluating their impact on HCBS outcomes.

Lastly, the majority of available studies were nonrandomized. Randomization to different HCBS approaches can lead to stronger inferences and support the choice of the best approach for a specific context.

3.2.3.2 Gaps in Patient Population and Outcome Measures

While this review evaluated the adults over age 60 years, often with disability and multiple morbidities, there is a paucity of data on population factors traditionally considered as health disparities, such as race, ethnicity, English language proficiency, gender identity, sexual orientation, and immigration status.

Person-centered outcomes are critical to measure person-centeredness in HCBS interventions, as suggested by the KIs. The objectives of person-centeredness in HCBS are to offer opportunities and flexibility for individuals to choose and control their lives without abandoning them to the choices they make. However, there is no consensus on how to measure person-centeredness, and the validity and reliability of existing measures have not been established. Our literature search identified only a few person-centered outcomes. Other individual outcome measures, including quality of life, satisfaction, and social isolation are also rarely reported in the HCBS literature.

Caregiver outcomes, affecting family members who provide direct care, DCWs, and clinical care teams, are less evaluated in the literature compared with clinical and health utilization outcomes.

3. Findings

3.2.3.3 Gaps in Person-Centered Planning

There are significant gaps in evidence as it relates to defining the populations most likely to benefit from person-centered planning approaches, identifying predetermined outcomes to define what success looks like, and the elements that are key to meeting these outcomes (e.g., caregiver/healthcare work role, training, supervision). Given the heterogeneity of the HCBS landscape regarding different populations, individual health and social outcomes, caregiver outcomes, economic outcomes, and care providers, future research is needed to clarify these gaps. Clearer descriptions of the details of person-centered planning in the published literature can support replication and implementation of research findings.

4. Summary and Implications

4. Summary and Implications

This technical brief summarizes the literature published about person-centered home and community-based services (HCBS) in adults aged 60 years or older with a functional limitation in home and community-based settings. This report provides an overview that maps the populations and interventions that have been studied, the available quality measures, and identified evidence gaps.

4.1 Strengths and Limitations

The comprehensive search for published and grey literature is strengthened by feedback from Key Informants (KIs) with diverse expertise and backgrounds including Area Agencies on Aging, Federal agencies, HCBS providers, HCBS researchers, and beneficiary advocates. Key limitations of HCBS literature relate to the difficulty in determining the extent of person-centeredness in the described interventions and the limited information on barriers and facilitators. Definitions of person-centeredness vary, and labeling an intervention as such may be a tokenistic approach without providing any components of person-centered HCBS in some cases. Many studies reported on clinical outcomes with less focus on health-related social needs, the latter being critical requirements for keeping older individuals and those with a functional limitation in their homes and communities.

The current literature does not explicitly evaluate HCBS with a complex intervention lens that focuses on interactions, effect modifiers, and determination of necessary and sufficient components of the intervention. Quantitative analytic methods of complex interventions are available and may advance the HCBS field,^{88, 89} but they are not commonly pursued in this context. Data on the workforce that delivers HCBS are needed for planning and optimal delivery.

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Abbreviations and Acronyms

ACSC	Ambulatory Care Sensitive Condition
ADL	Activities of Daily Living
AHRQ	Agency for Healthcare Research and Quality
CAHPS	Consumer Assessment of Healthcare Providers and Systems
DCW	Direct Care Workers
EPC	Evidence-based Practice Center
GQ	Guiding Question
HCBS	Home and Community-Based Services
Home DCE	Home Dialysis Care Experience
KI	Key Informant
IADL	Instrumental Activity of Daily Living
LTSS	Long-term Services and Supports
MCO	Managed Care Organizations
MLTSS	Managed Long-Term Services and Supports
n	Number
NASDDDS	National Association of State Directors of Developmental Disabilities Services
NCI-AD	National Core Indicators for Aging and Disabilities
NCI-ID	National Core Indicators for Intellectual and Developmental Disabilities
NCQA	National Committee for Quality Assurance
NFLOC	Nursing Facility Level of Care
NLP	Natural Language Processing
NQF	National Quality Forum
PAH	Potentially Avoidable Hospitalizations
PHQ-9	Patient Health Questionnaire-9
PQI	Prevention Quality Indicators
POM	Personal Outcome Measures
QI	Quality Indicator
QoL	Quality of Life
RCT	Randomized Controlled Trial
RTCOM	Research and Training Center on HCBS Outcome Measurement
TOO	Task Order Officer
UNC-CEAL	University of North Carolina-Center for Excellence in Assisted Living
U.S.	United States

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Appendix A. Search Strategy

Ovid

Database(s): APA PsycInfo 1806 to July Week 4 2023, EBM Reviews - Cochrane Central Register of Controlled Trials December 2023, EBM Reviews - Cochrane Database of Systematic Reviews 2005 to December 07, 2023, Embase 1974 to December 07, 2023, Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions 1946 to December 07, 2023

Search Strategy:

- | # | Searches |
|----|--|
| 1 | exp community health services/ or exp home care services/ |
| 2 | home care/ or community services/ |
| 3 | exp Senior Centers/
((HCBS and (home or homes or communit* or "independent living" or "assisted living")) or "Community-based care" or "Community-based health care" or "Community-based healthcare" or "Community-based Service*" or "Home care Service*" or "Home health care Service*" or "Home healthcare Service*" or "Home-based care" or "Home-based health care" or "Home-based healthcare" or "Home-based Service*" or "senior center" or "senior centers" or "senior centre" or "senior centres").ti,ab,kf. |
| 4 | |
| 5 | 1 or 2 or 3 or 4 |
| 6 | exp Occupational Therapy/ |
| 7 | exp Speech Therapy/ |
| 8 | exp Physical Therapy/ |
| 9 | exp Physical Therapy Modalities/ |
| 10 | exp Case Management/ |
| 11 | exp Caregivers/ed [Education] |
| 12 | exp Health Promotion/ |
| 13 | exp Hospices/ |
| 14 | exp caregiver/ and exp education/ |
| 15 | exp Hospice/ |
| 16 | exp Education/ and exp Caregivers/ |
| 17 | exp Food Services/ |
| 18 | exp "Activities of Daily Living"/ |
| 19 | exp Mental Health Services/ |
| 20 | exp Legal Services/ |
| 21 | exp Rehabilitation, Vocational/ |
| 22 | exp Cognitive Rehabilitation/ |
| 23 | exp Career Development/ |
| 24 | exp Counseling/ |

- 25 exp Crisis Intervention/
 26 Psychological Assessment/
 27 Prescription Drugs/
 28 Nursing, Private Duty.hw.
 29 exp Psychosocial Rehabilitation/
 30 exp Respiratory Therapy/
 (((assist* or help* or manag*) adj3 (financial or legal)) or ((assist* or help*) adj3 (dressing or bathing or toilet* or eating or eat or transfer* or bed or chair*)) or ((behavioral or mental) adj5 service*) or ((Caregiver* or client or clients or patient or patients or participant*) adj3 (train* or educat* or instruct* or teach*)) or ((disease or fall or falls) adj3 prevent*) or ((Home or Vehicle) adj3 access*) or ((information or referral) adj3 service*) or ((job or employment or vocational) adj3 (support* or rehab* or development)) or ((Medication* or drug* or pharma*) adj3 (Assess* or Manag*)) or ((Occupational or speech or language or hearing or physical) adj3 (therap* or treatment* or intervention*)) or ((phone or telephone) adj3 reassur*) or ((will or wills) adj3 prepar*) or (Equipment and Technology) or (home adj3 (repair* or modification*)) or (home adj3 safety adj3 assess*) or "Adult Day Health*" or "Adult Day Service*" or "adult daycare*" or "Assertive Community Treatment*" or "Behavior Support" or "career development" or "Career Planning" or "Case management" or Chore or chores or "Clinic Services" or "Cognitive Rehabilitative Therapy" or "Community Integration" or "Community Transition Service*" or Companion or companion* or
 31 Counseling or "crisis Intervention" or "Day Habilitation" or "day support" or "day supports" or "Day Treatment*" or "Dementia care" or "Dental Service*" or "Education Service*" or "educational service*" or "food service*" or "functional disabilit*" or "Goods and Services" or "Group Living" or "Health Assessment" or "Health Monitoring" or "Health promotion" or "Home Health Aide*" or "home respite" or "Home-Based Habilitation" or "home-delivered food*" or "home-delivered meal*" or Homemaker* or hospice or "Housing Consult*" or "individualized care" or Interpreter* or "Live-In Caregiver*" or "meal service*" or "meal site*" or "Medical Day Care for Children" or "medical equipment" or "medical Supplies" or "Memory care" or "Mental Health Assessment" or "Nutrition Consultat*" or "Partial Hospitalization" or "Participant Direction" or "Peer Specialist*" or "Personal assistance" or "Personal Care" or "Personal Emergency Response System*" or "personalized care" or "physical access" or "Physician Service*" or "Prescription Drugs" or "Prevocational Service*" or "Private Duty Nurs*" or "Psychological Assessment*" or "Psychosocial Rehabilitation" or "Respiratory Therapy" or "Round-The-Clock" or "Skilled Nurs*" or transportation).ti,ab,kf.
 32 or/6-31
 33 exp Home Environment/
 34 exp Assisted Living Facilities/
 35 exp Independent Living/
 36 exp Assisted Living/
 37 (((live or living) adj3 independent*) or "assisted living" or home or homes).ti,ab,kf.
 38 33 or 34 or 35 or 36 or 37
 39 32 and 38

40 5 or 39

41 Patient-Centered Care.hw.

42 (("patient focused" or "person focused" or "patient centered" or "person centered" or "patient directed" or "person directed") adj3 (care or plan*)).ti,ab,kf.

43 41 or 42

44 40 and 43

45 limit 44 to yr="2019 -Current"

46 remove duplicates from 45

47 44 not 46

48 remove duplicates from 47

49 46 or 48

PREPUBLICATION FINAL

Scopus

- 1 TITLE-ABS-KEY((HCBS and (home or homes or communit* or "independent living" or "assisted living")) or "Community-based care" or "Community-based health care" or "Community-based healthcare" or "Community-based Service*" or "Home care Service*" or "Home health care Service*" or "Home healthcare Service*" or "Home-based care" or "Home-based health care" or "Home-based healthcare" or "Home-based Service*" or "senior center" or "senior centers" or "senior centre" or "senior centres")
- 2 TITLE-ABS-KEY(((assist* or help* or manag*) W/3 (financial or legal)) or ((assist* or help*) W/3 (dressing or bathing or toilet* or eating or eat or transfer* or bed or chair*)) or ((behavioral or mental) W/5 service*) or ((Caregiver* or client or clients or patient or patients or participant*) W/3 (train* or educat* or instruct* or teach*)) or ((disease or fall or falls) W/3 prevent*) or ((Home or Vehicle) W/3 access*) or ((information or referral) W/3 service*) or ((job or employment or vocational) W/3 (support* or rehab* or development)) or ((Medication* or drug* or pharma*) W/3 (Assess* or Manag*)) or ((Occupational or speech or language or hearing or physical) W/3 (therap* or treatment* or intervention*)) or ((phone or telephone) W/3 reassur*) or ((will or wills) W/3 prepar*) or (Equipment and Technology) or (home W/3 (repair* or modification*)) or (home W/3 safety W/3 assess*) or "Adult Day Health*" or "Adult Day Service*" or "adult daycare*" or "Assertive Community Treatment*" or "Behavior Support" or "career development" or "Career Planning" or "Case management" or Chore or chores or "Clinic Services" or "Cognitive Rehabilitative Therapy" or "Community Integration" or "Community Transition Service*" or Companion or companion* or Counseling or "crisis Intervention" or "Day Habilitation" or "day support" or "day supports" or "Day Treatment*" or "Dementia care" or "Dental Service*" or "Education Service*" or "educational service*" or "food service*" or "functional disabilit*" or "Goods and Services" or "Group Living" or "Health Assessment" or "Health Monitoring" or "Health promotion" or "Home Health Aide*" or "home respite" or "Home-Based Habilitation" or "home-delivered food*" or "home-delivered meal*" or Homemaker* or hospice or "Housing Consult*" or "individualized care" or Interpreter* or "Live-In Caregiver*" or "meal service*" or "meal site*" or "Medical Day Care for Children" or "medical equipment" or "medical Supplies" or "Memory care" or "Mental Health Assessment" or "Nutrition Consultat*" or "Partial Hospitalization" or "Participant Direction" or "Peer Specialist*" or "Personal assistance" or "Personal Care" or "Personal Emergency Response System*" or "personalized care" or "physical access" or "Physician Service*" or "Prescription Drugs" or "Prevocational Service*" or "Private Duty Nurs*" or "Psychological Assessment*" or "Psychosocial Rehabilitation" or "Respiratory Therapy" or "Round-The-Clock" or "Skilled Nurs*" or transportation)
- 3 TITLE-ABS-KEY(((live or living) W/3 independent*) or "assisted living" or home or homes)
- 4 1 or (2 and 3)
- 5 TITLE-ABS-KEY(("patient focused" or "person focused" or "patient centered" or "person centered" or "patient directed" or "person directed") W/3 (care or plan*))
- 6 4 and 5
- 7 INDEX(embase) OR INDEX(medline) OR PMID(0* OR 1* OR 2* OR 3* OR 4* OR 5* OR 6* OR 7* OR 8* OR 9*)
- 8 6 and not 7

ClinicalTrials.Gov

Other terms

Search 1

Intervention

"Community-based care" OR "Community-based health care" OR "Community-based healthcare" OR "Community-based Service*" OR "Home care Service*" OR "Home health care Service*" OR "Home healthcare Service*"

Other terms

"patient focused" OR "person focused" OR "patient centered" OR "person centered" OR "patient directed" OR "person directed"

Search 2

Intervention

"Home-based care" OR "Home-based health care" OR "Home-based healthcare" OR "Home-based Service*" OR "senior center" OR "senior centers" OR "senior centre" OR "senior centres"

Other terms

"patient focused" OR "person focused" OR "patient centered" OR "person centered" OR "patient directed" OR "person directed"

Grey Literature

Google

("patient focused" OR "person focused" OR "patient centered" OR "person centered" OR "patient directed" OR "person directed")

AND (HCBS OR "Home-based services" OR "community-based services") AND (outcome OR outcomes OR quality)

Appendix B. Excluded Studies

Population not of Interest

1. Rietkerk W, Smit MF, Wynia K, et al. Explaining experiences of community-dwelling older adults with a pro-active comprehensive geriatric assessment program - a thorough evaluation by interviews. *BMC geriatr.* 2019 01 14;19(1):12. doi: <https://dx.doi.org/10.1186/s12877-018-1025-7>. PMID: 30642257.
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Intervention not of Interest

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Outcome not of Interest

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Appendix C. Study Findings From the Included Systematic Reviews

Table C.1. Findings of the included systematic reviews

Author, year	Goal	Review Limitations*	Summarized Evidence	Main Findings
Liao, 2023 ¹	To describe the experience of older adults, healthcare providers and caregivers on implementing person-centered HCBS interventions in the community	No major concerns	12 Qualitative studies published 2006-2023, mostly from Europe and Canada	<ul style="list-style-type: none"> • The review identified three themes: <ul style="list-style-type: none"> ○ Capacity of older people, healthcare providers, and caregivers: <ul style="list-style-type: none"> ▪ Lack of person-centered HCBS knowledge and skills, ▪ Negative attitudes toward shared decision making, ▪ Lack of formal training ○ Opportunities in the implementation of person-centered HCBS: <ul style="list-style-type: none"> ▪ Lack of coordination in resource allocation, ▪ Strengthening multidisciplinary teamwork, ▪ Establishing a desirable environment and time constraints ○ Motivation in implementing person-centered HCBS: <ul style="list-style-type: none"> ▪ Encouraging self-reflection and regulation ▪ Respecting the autonomy of older people ▪ Lack of clear reward and empowerment mechanisms ▪ Need for being resilient and optimistic

Author, year	Goal	Review Limitations*	Summarized Evidence	Main Findings
Kane, 2023 ²	To evaluate training and support needs of homecare workers providing person-centered care to clients living with dementia	No concerns	1 RCT and 6 qualitative studies	<ul style="list-style-type: none"> Four themes were identified: <ul style="list-style-type: none"> Training and education challenges and facilitators Social isolation and the importance of peer support Emotional attachments and distress experienced by homecare workers Working with families and its emotional impact on homecare workers To improve person-centered care, homecare workers need dementia-specific training, emotional and peer support, and support to manage relationship with clients' families.
Lizano-Diez, 2022 ³	To evaluate patient support programs (not exclusively for older or disabled individuals)	No risk of bias evaluation. Narrative synthesis	54 Studies (3 RCTs, 64 home-based care initiatives)	<ul style="list-style-type: none"> Patient support programs include interventions such as home-based care, individualized medication counseling, support, training, and home delivery of medicines and/or devices. Most services were provided by nurses (73%), addressed cancer patients (34%), and incorporated telepharmacy (36%). Home-based services and patient support programs showed a positive impact on patients' adherence to medication, patient satisfaction, QoL and were associated with substantial cost savings.
Grover, 2021 ⁴	To define person-centered care and identify its core elements, facilitators, and barriers	Umbrella review, no major concerns	10 Systematic reviews	<ul style="list-style-type: none"> The review identified person-centered care definitions. <ul style="list-style-type: none"> Core elements of the definitions include: <ul style="list-style-type: none"> Patient empowerment Patient individuality Biopsychosocial approach Implementation factors focused on: <ul style="list-style-type: none"> Communication Training healthcare providers Organizational structure

Author, year	Goal	Review Limitations*	Summarized Evidence	Main Findings
Sanerma, 2020 ⁵	To define client-centered HCBS and identify its core elements, facilitators, and barriers in older individuals	No major concerns	24 Qualitative studies published 2007-2020, mostly from Europe and Canada	<ul style="list-style-type: none"> • Core elements of client-centered HCBS: <ul style="list-style-type: none"> ○ Person' involvement in their own care <ul style="list-style-type: none"> ▪ Selfcare ▪ Decision making ▪ Satisfactory daily life ○ Family members' and care partners' participation <ul style="list-style-type: none"> ▪ Commitment ▪ Competence ○ Communication and cooperation <ul style="list-style-type: none"> ▪ Communication ▪ Empowerment ▪ Partnership ○ Evidence-based service competence <ul style="list-style-type: none"> ▪ Delivery and organization of services ▪ Implementation of services ▪ Versatile clinical skills ▪ Quality outcomes ▪ Personal wellbeing

Author, year	Goal	Review Limitations*	Summarized Evidence	Main Findings
John, 2020⁶	To evaluate the effectiveness of patient-centered medical home-based model in chronic disease management	The wide scope and standardization of outcome measures limits evidence translation	78 RCTs and 7 nonrandomized studies (3 retrospective cohort, 2 prospective cohort, and 2 pre/post studies) (60,617 patients)	<ul style="list-style-type: none"> • Patient-centered medical home-based model commonly include engagement through education and self-management, and care coordination and team-based care. • Patient-centered medical home-based model was associated with significant improvements in: <ul style="list-style-type: none"> ○ Depression episodes (SMD: -0.24; 95% CI: -0.35, -0.14; I²: 76%) and increased odds of remission (OR: 1.79; 95% CI: 1.46, 2.21; I²: 0%,) ○ Improvements in QoL (SMD: 0.10; 95% CI: 0.04, 0.15; I²: 51%) ○ Self-management outcomes (SMD: 0.24; 95% CI: 0.03, 0.44; I²: 83%), and hospital admissions (OR: 0.83; 95% CI: 0.70, 0.98; I²: 0%,). ○ Improvements in surrogate outcomes: <ul style="list-style-type: none"> ▪ Blood pressure, ▪ A1C ▪ LDL-cholesterol, but not total cholesterol • The incremental cost of patient-centered medical home-based model was described as small (SMD: 0.17; 95% CI: 0.08, 0.26; I²: 82%).
Bonenkamp, 2020⁷	To compare QoL between home dialysis and in-center dialysis. Population is not necessarily > 60 years old. Intervention is not necessarily person-centered.	More than half of the studies with moderate or high risk of bias	41 Cross-sectional studies	<ul style="list-style-type: none"> • Meta-analysis showed better physical QoL scores in home dialysis patients compared with in-center HD patients (SMD: 0.14; 95% CI: 0.04 to 0.24), with high heterogeneity. • Mental QoL showed no difference.

Author, year	Goal	Review Limitations*	Summarized Evidence	Main Findings
Vaartio-Rajalin, 2019⁸	To describe person-centered home-based rehabilitation interventions for people with Parkinson's disease	No risk of bias evaluation. No clear definition of the design of eligible studies	67 included studies (30 RCTs, 5 systematic reviews, 16 cross-sectional studies)	<ul style="list-style-type: none"> Physical activity interventions were the most common form of rehabilitation (e.g., walking, individually tailored exercise programs) and were conducted outside the home even though they were suitable for a home setting. These interventions improved several physical outcomes, QoL, well-being and activities of daily living functions. Digital devices were used in some interventions. Cognitive and psychosocial rehabilitation were much less researched. The majority of interventions were planned without discussing in advance with the people with Parkinson's disease about their preferences, needs or values. Only a few studies focused on an interprofessional approach.
Kwan, 2019⁹	To evaluate older people's views and experiences about personal care and practical support at home	No concerns	17 Studies (conducted in the U.K., published 2007-2013, 6 qualitative, 5 cross-sectional survey studies, and 6 mixed methods)	<ul style="list-style-type: none"> Nine themes were identified by older people: <ul style="list-style-type: none"> Characteristics and competency of home care workers, Promoting independence, Being listened to and respected, Practical support and flexibility of care, Communication barriers, Time to care and build working relationship, Continuity and consistency, Outcome-focused approach, Ability to manage own budget to organize care

Author, year	Goal	Review Limitations*	Summarized Evidence	Main Findings
Vaartio-Rajalin, 2018¹⁰	To describe professional care at home	Scoping review. No risk of bias evaluation. No clear definition of the design of eligible studies	28 published and 7 unpublished studies	<ul style="list-style-type: none"> • Person-centeredness is a common aim of professional care at home. • The competence framework for care at home is not explicit. • Consumers and their caregivers were satisfied with care at home but no consensus on clinical or economic benefits over inpatient care.
Baird, 2018¹¹	To evaluate the effect of home care case managers working with older adults with multiple chronic conditions	Scoping review. No risk of bias evaluation. Narrative synthesis	14 Studies, mostly qualitative (8 qualitative, 2 RCTs, 1 retrospective cohort, 2 mixed methods)	<ul style="list-style-type: none"> • Home care case managers working with older adults with multiple chronic conditions followed most case management standards, but their use of professional and clinical integrated care functions was inconsistent.
Hofmeister, 2018¹²	To summarize the quality and primary outcomes measured within the palliative care in the home literature	Scoping review	53 Studies (17 RCTs, 10 qualitative, 18 retrospective cohort, 4 cross-sectional)	<ul style="list-style-type: none"> • Five types of intervention components were identified: <ul style="list-style-type: none"> ○ Accessibility of healthcare ○ Caregiver support ○ Individualized patient centered care ○ Multidisciplinary care provision ○ Quality improvement. • Primary outcomes were: <ul style="list-style-type: none"> ○ Resource use ○ Symptom burden ○ QoL ○ Satisfaction ○ Caregiver distress ○ Place of death ○ Cost analysis ○ Described experiences • The majority of studies were of moderate or unclear quality (low risk of bias studies were only 20–40%).

Author, year	Goal	Review Limitations*	Summarized Evidence	Main Findings
Kim, 2017¹³	To evaluate the effectiveness of person-centered care for people with dementia	No concerns	19 Studies (2 from home care settings, 4 nonrandomized studies, 15 RCTs, 3,985 participants)	<ul style="list-style-type: none"> • Pooled data from RCTs favored person-centered care in reducing agitation, neuropsychiatric symptoms, and depression and improving QoL. • Subgroup analysis identified greater effectiveness of person-centered care when implemented for people with less severe dementia. Individualized activities resulted in a significantly greater beneficial effect than standard care. • Long-term, staff education, and cultural change interventions had a greater effect on improving QoL for people with dementia.
Cochrane, 2016¹⁴	To compare home-based reablement (restorative care) with usual home-care services	No concerns	2 RCTs (811 people)	<ul style="list-style-type: none"> • Reablement is <ul style="list-style-type: none"> ◦ Restorative ◦ Goal-oriented ◦ Time-limited (usually 6–12 weeks) • Includes occupational therapy and physical therapy using: <ul style="list-style-type: none"> ◦ Work simplification ◦ Assistive technology ◦ Chronic disease self-management ◦ Fall-prevention strategies ◦ Medication management. • Very low-quality evidence suggested that reablement maybe slightly more effective than usual care in improving function at 9–12 months with no difference in mortality or rates of unplanned hospital admission at 24 months.
Ratti, 2016¹⁵	To evaluate the effectiveness of person-centered planning for people with intellectual disabilities	No concerns	16 Studies (5 retrospective cohort, 2 pre/post studies, 5 qualitative and 4 mixed methods)	<ul style="list-style-type: none"> • Low quality of evidence suggested that person-centered planning may have a positive, yet moderate, impact on some outcomes for individuals with intellectual disabilities, particularly community-participation, participation in activities and daily choice-making. • For other outcomes such as employment the findings were inconsistent.

Author, year	Goal	Review Limitations*	Summarized Evidence	Main Findings
Jutkowitz, 2016 ¹⁶	To evaluate the efficacy of nonpharmacological interventions to manage agitation and aggression in dementia	No concerns	19 RCTs (3 evaluated PCC in a nursing home and one evaluated staff training in assisted living residents)	<ul style="list-style-type: none"> Evidence was insufficient regarding the efficacy of nonpharmacological care-delivery interventions to reduce agitation or aggression in people with dementia.
Deek, 2016 ¹⁷	To evaluate family-centered approaches in chronic diseases in adults	No concerns	10 Studies (1 retrospective cohort, 9 RCTs, 1,823 patients with their family caregivers)	<ul style="list-style-type: none"> Family-centered approaches were associated with improvements in readmission rates, emergency department presentations, and anxiety levels. Elements of effective interventions were active learning strategy and transitional care with appropriate followup
Radhakrishnan, 2016 ¹⁸	To evaluate barriers and facilitators for telehomecare programs for chronic disease management.	No concerns. Narrative synthesis	5 nonrandomized studies (1 retrospective, 3 cross-sectional, 1 pre/post studies), 10 qualitative studies, 1 mixed methods study.	<ul style="list-style-type: none"> Sustainability of telehomecare programs was impacted by: <ul style="list-style-type: none"> Perceptions on effectiveness Tailoring to patient characteristics and needs Relationship and communication between patient, nurse, and other healthcare professionals Home health organizational process and culture Technology quality, capability, and usability
Brasure, 2016 (AHRQ) ¹⁹	To evaluate the efficacy of nonpharmacological interventions to manage agitation and aggression in dementia	No concerns	126 RCTs (Not exclusively designated as HCBS)	<ul style="list-style-type: none"> For managing agitation/aggression in people with dementia, supported no difference compared with usual care for: <ul style="list-style-type: none"> Patient-level interventions, Interventions tailored to recipients' skills and/or interests Care delivery-level interventions (dementia care mapping and person-centered care)

Author, year	Goal	Review Limitations*	Summarized Evidence	Main Findings
Ishani, 2015 ²⁰	To compare effectiveness between home dialysis and in-center dialysis. Population is not necessarily > 60 years old. Intervention is not necessarily person-centered.	No concerns	3 RCTs and several registry studies	<ul style="list-style-type: none"> Low strength of evidence suggesting home dialysis may be associated with improved survival compared with in-center dialysis (although inconsistent findings across studies). Home dialysis patients were more likely to switch dialysis modality.
Walker, 2015 ²¹	To evaluate patient and caregiver perspectives on home hemodialysis.	No concerns	24 Qualitative studies	<ul style="list-style-type: none"> Patients and caregivers perceive that home hemodialysis offers the opportunity to thrive; improves freedom, flexibility, and well-being; and strengthens relationships. However, some voice anxiety and fear about starting home hemodialysis due to the confronting nature of the treatment and isolation from medical and social support.
Livingston, 2014 ²²	To evaluate the efficacy of nonpharmacological interventions to manage agitation and aggression in dementia	No concerns. Narrative synthesis	33 RCTs	<ul style="list-style-type: none"> Immediate decrease and decrease for up to 6 months afterwards in symptomatic and severe agitation was found with: <ul style="list-style-type: none"> Person-centered care Communication skills training Adapted dementia care mapping in care homes.
Livingston, 2014 ²³	To evaluate the efficacy of nonpharmacological interventions to manage agitation and aggression in dementia	No concerns	160 Studies (33 RCTs)	<ul style="list-style-type: none"> No stratification by residence status (mostly nursing home residents). Person-centered care, communication skills and dementia care mapping (all with supervision), sensory therapy activities, and structured music therapies reduced agitation in dementia.
Joo, 2013 ²⁴	To evaluate nurse-led community-based case management (not exclusively for older or disabled individuals)	No risk of bias evaluation. Narrative synthesis	18 Studies (7 RCTs, 5 retrospective cohort, 2 prospective cohort, 1 qualitative study, 1 mixed methods) published 2000 to 2013	<ul style="list-style-type: none"> Narrative synthesis suggested that nurse-led community-based case management reduced hospital access outcomes, especially readmissions and increased cost effectiveness, patient clinical outcomes (e.g., A1C, cholesterol, diastolic BP and LDL cholesterol, suicide attempts, legal issues related to substance abuse) and patient centered outcomes (e.g., satisfaction, wellness, QoL, holistic outcomes, adaptation to change in health).

Author, year	Goal	Review Limitations*	Summarized Evidence	Main Findings
Oeseburg, 2009²⁵	To evaluate the effects of patient advocacy case management on service use and healthcare costs for older people with impairments or adults with a chronic somatic disease living in the community	No concerns	8 RCTs	<ul style="list-style-type: none"> • Patient advocacy case management for impaired older people or adults with a chronic somatic disease living in the community did not increase service use and costs and was effective in decreasing service use and costs in two studies. • Outcomes evaluated: <ul style="list-style-type: none"> ○ Hospital admission ○ Hospital LOS ○ ED visits ○ Nursing home admission ○ Healthcare cost

Abbreviations: AHRQ = Agency for Healthcare Research and Quality; BP = blood pressure; CI = confidence interval; ED = Emergency department; HCBS = home and community-based services; HD = hemodialysis; LDL = low-density lipoprotein; LOS = length of stay; PCC = person-centered care; QoL = quality of life; RCT = randomized clinical trial; SMD = standard mean difference; OR = odds ratio U.K. = United Kingdom

*: Review limitations were based on selected items from AMSTAR.

Appendix D Characteristics of Included Primary Studies

Table D.1. Characteristics of included primary studies: Randomized controlled trials

Author, Year;	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Reeves, 2019 ²⁶	3 months	<p><u>Population:</u> Adult acute patients with stroke returning home within 1 month of hospital discharge</p> <p><u>Age:</u> Mean (SD): 66.2 (13.2) years</p> <p><u>Geography:</u> Michigan</p> <p><u>Race/Ethnicity:</u> White: 79%</p> <p><u>Sex:</u> Female: 49%</p> <p><u>Comorbidities:</u> Stroke: 16%, Myocardial infarction: 9%, Coronary Artery Disease: 22%, Atrial Fibrillation: 14%, Diabetes: 37%, Hypertension: 77%, Hyperlipidemia: 49%</p> <p><u>Social Situation:</u> Caregiver lives with patient: 76%, caregiver relationship-spouse: 60%</p> <p><u>Clinical Needs:</u> 6-item cognitive screen score (SIS-6): mean (SD): 5.4 (1.0)</p>	<p>Home-based social worker-led case management (SWCM): in-home and phone-based case management services (n=88) vs. Home-based social worker-led case management + website (SWCM+website): in-home and phone-based case management services + website with patient-orientated information covering stroke education, prevention, recovery, and community resources (n=90); vs. Usual care: hospitals' standard postdischarge instructions, services, and recommendations, including medication lists, education materials, followup instructions, and referrals to medical appointments, and postacute services (n=87)</p>	<p>Hospital readmission: SWCM vs usual care: OR: 1.21 (95% CI: 0.59, 2.51); SWCM+website vs usual care: OR: 1.03 (95% CI: 0.49, 2.16); SWCM+website vs SWCM: OR: 0.85 (95% CI: 0.42, 1.74)</p> <p>Activities of daily living/instrumental activities of daily living combined score: SWCM vs. usual care: MD: 0.54 (95% CI: -0.51, 1.59); SWCM+website vs. usual care: MD: -0.87 (95% CI: -1.92, 0.18)</p> <p>Stroke recurrence: SWCM vs. usual care OR: 0.69 (95% CI: 0.21, 2.26); SWCM+website vs usual care: OR: 1.76 (95% CI: 0.66, 4.70); SWCM+website vs. SWCM: OR: 2.55 (95% CI: 0.86, 7.58)</p> <p>PROMIS Global-10: SWCM+ website vs. usual care: MD: 3.37 (95% CI: 1.41, 5.33); SWCM+website vs. SWCM only: MD: 2.40 (95% CI: 0.46, 4.34); SWCM vs. usual care: MD: 0.97 (95% CI: -1.01, 2.95); SWCM+website vs. SWCM: MD: 1.32 (95% CI: -1.24 to 3.88)</p> <p>Mediating factors: No significant difference on age, stroke severity, discharge destination, and caregiver</p>

Author, Year;	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Reisberg, 2017 ²⁷	7 months	<u>Population:</u> Adults with moderate-to-severe Alzheimer's disease <u>Age:</u> Mean (range) 78.9 (54-92) years <u>Geography:</u> New York <u>Race/ethnicity:</u> NR <u>Sex:</u> Female: 75% <u>Comorbidities:</u> NR <u>Social Situation:</u> NR <u>Clinical Needs:</u> Required assistance with activities of daily living	Comprehensive, individualized, person-centered management program: caregiver training, management assessment, therapeutic home visits, and caregiver support group meetings (n=10) vs. Usual community care plus financial compensation (n=10)	<p>Functioning: Improvement on the Alzheimer's Disease Cooperative Study Activities of Daily Living Inventory modified for more severe dementia abbreviated version (higher score indicates greater capacities): Person-centered management program vs. Usual care: 12.3 points (p<0.001)</p> <p>Behavior: the Behavioral Pathology in Alzheimer's Disease Frequency-Weighted Severity Scale (higher score indicates increased magnitude and frequency of behavioral disturbance): Person-centered management program vs. Usual care: -16.5 (p<0.05)</p> <p>Cognition: Neither objective cognitive assessment showed significant between-group differences at any observation period</p>
Galik, 2015 ²⁸	6 months	<u>Population:</u> Dementia patients in Assisted Living <u>Age:</u> Mean age (SD) 83.7 (7.1) years <u>Geography:</u> Maryland <u>Race/Ethnicity:</u> White: 92% <u>Sex:</u> Female: 71% <u>Comorbidities:</u> Number of comorbidities (SD): 6.9 (2.1) <u>Social Situation:</u> Unmarried: 76% <u>Clinical Needs:</u> Living in assisted living <u>Social Situation:</u> NR <u>Clinical Needs:</u> NR	Function Focused Care: evaluation of person-environment fit; education; establishing care goals for residents; mentoring/monitoring and sustainability of the intervention (n=48) vs. Education only: direct care workers, other members of the healthcare team, families, and residents (n=48)	<p>Hospitalization: Function Focused Care vs. Education only: 0 vs 0</p> <p>Falls: Function Focused Care vs. Education only: OR: 2.28 (95% CI: 0.97 to 5.35) No significant difference in mortality, agitation or apathy, depressive symptoms</p>

Author, Year;	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Labson, 2013; ^{29, 30}	3 months	<p><u>Population:</u> Kaiser Permanente's In-Home Palliative Care program: Homebound, terminally ill patients with a prognosis of approximately 1 year or less to live</p> <p><u>Age:</u> Mean (SD): 74.0 (12.0) years</p> <p><u>Geography:</u> Hawaii and Colorado</p> <p><u>Race/Ethnicity:</u> Asian/Pacific Islanders: 18%, Hawaiian: 13%, Latino: 4%</p> <p><u>Sex:</u> Female: 49%</p> <p><u>Comorbidities:</u> Diagnosis with cancer: 47%; CHF: 33%; COPD: 21%</p> <p><u>Social Situation:</u> Live alone: 26%</p> <p><u>Clinical Needs:</u> Homebound, terminally ill patients with a prognosis of approximately 1 year or less to live</p>	Home health-based palliative care programs: Interdisciplinary team approach with home visits by all team members, ongoing care management, telephone support, and advanced-care planning (n=155) vs. Usual care: various amounts and levels of home health services, acute care services, primary care services, and hospice care (n=155)	<p>Mortality: Kaiser Permanente's in-home palliative care program vs. Usual care: No significant difference (p>0.05)</p> <p>Satisfaction: Kaiser Permanente's in-home palliative care program vs. Usual care: OR: 1.79 (95% CI: 0.65, 4.29)</p> <p>ER visits: Kaiser Permanente's in-home palliative care program vs. Usual care: 20% vs. 33% (p=0.01)</p> <p>Hospitalization: Kaiser Permanente's in-home palliative care program vs. Usual care: 36% vs. 59% (p<0.001)</p>

Author, Year;	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Resnick, 2011 ³¹	12 months	<p><u>Population:</u> Older adults living in assisted living facilities who require assistance with activities of daily living</p> <p><u>Age:</u> Mean (SD): 87.7 (5.7) years</p> <p><u>Geography:</u> Maryland</p> <p><u>Race/Ethnicity:</u> White: 93%, Black: 4%, Asian: 1%, Native American: 1%</p> <p><u>Sex:</u> Female: 80%</p> <p><u>Comorbidities:</u> NR</p> <p><u>Social Situation:</u></p> <p>Married: 10%</p> <p>Clinical Needs: Living in assisted living facilities who require assistance with activities of daily living</p>	<p>Function-Focused Care in Assisted Living: environmental and policy assessments; education, establishing goals, mentoring and motivating (n=93) vs. Education only: education of nursing staff, other members of the interdisciplinary team, residents, and families using previously established materials and adult learning techniques (n=78)</p>	<p>Mortality:</p> <p>Function-Focused Care in Assisted Living vs. Education only: OR: 0.70 (95% CI: 0.23, 2.18)</p> <p>Nonfall hospitalizations:</p> <p>Function-Focused Care in Assisted Living vs. Education only: OR: 0.28 (95% CI: 0.07, 1.11)</p> <p>Function decline: Mean 6.95 points in control vs 4.33 points in intervention, p=0.01</p> <p>Falls:</p> <p>Function-Focused Care in Assisted Living vs. Education only: OR: 1.04 (95% CI: 0.57, 1.91)</p> <p>Injuries:</p> <p>Assisted Living vs. Education only: OR: 1.54 (95% CI: 0.73, 3.24)</p> <p>ED visits for falls:</p> <p>Function-Focused Care in Assisted Living vs. Education only: OR: 2.62 (95% CI: 0.51, 13.37)</p> <p>No significant difference in moderate-level physical activity, counts of activity, and walking 50 yards.</p>

Author, Year;	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Sommers, 2000 ³²	36 months	<u>Population:</u> Community-dwelling senior patients with chronic illnesses and functional deficits <u>Age: Mean</u> (SD) 77.5 (6.7) years <u>Geography:</u> California <u>Race/Ethnicity:</u> White: 82.1% <u>Sex:</u> Female: 68.5% <u>Comorbidities:</u> Cancer: 12%, Respiratory disease: 20.1%, Gastrointestinal Tract Disease: 17.5%, Hypertension: 46.5%, Heart Disease: 15.9%, Diabetes: 17.9%, Stroke: 11% <u>Social Situation:</u> NR <u>Clinical Needs:</u> Unable to carry out at least 1 instrumental activity of daily living: getting around ,outside the home, meal preparation and household chores, taking medications, use of the telephone, and money management	Senior Care Connections: A collaboration between primary care physicians, nurses, and social workers, the intervention included home visits, health risks and frailty scores, risk reduction planning and treatment planning, health status monitoring between office visits through contacts by telephone, home visit, small group session, or office or hospital visit at least once every 6 weeks, and progress review (n=280) vs. Usual care from primary care physician only (n=263)	Mortality: Senior Care Connections vs. Usual Care: OR: 0.93 (95% CI: 0.53, 1.65) Hospital admissions: Senior Care Connections vs. Usual Care: OR: 0.63 (95% CI: 0.41, 0.96) ≥1 60-day readmissions: Senior Care Connections vs. Usual Care: OR: 0.26 (95% CI: 0.08, 0.84) ≥1 ED visits: Senior Care Connections vs. Usual Care: OR: 1.51 (95% CI: 0.79, 2.90) ≥1 skilled nursing facility admission: Senior Care Connections vs. Usual Care: OR: 1.37 (95% CI: 0.72, 6.16)

Author, Year;	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Sommers, 2000 ³²	36 months	<p><u>Population:</u> Community-dwelling senior patients with chronic illnesses and functional deficits</p> <p><u>Age:</u> Mean (SD) 77.5 (6.7) years</p> <p><u>Geography:</u> California</p> <p><u>Race/Ethnicity:</u> White: 82.1%</p> <p><u>Sex:</u> Female: 68.5%</p> <p><u>Comorbidities:</u> Cancer: 12%, Respiratory Disease: 20.1%, Gastrointestinal Tract Disease: 17.5%, Hypertension: 46.5%, Heart Disease: 15.9%, Diabetes: 17.9%, Stroke: 11%</p> <p>Social Situation: NR</p> <p><u>Clinical Needs:</u> Unable to carry out at least 1 instrumental activity of daily living: getting around, outside the home, meal preparation and household chores, taking medications, use of the telephone, and money management</p>	Senior Care Connections: A collaboration between primary care physicians, nurses, and social workers, the intervention included home visits, health risks and frailty scores, risk reduction planning and treatment planning, health status monitoring between office visits through contacts by telephone, home visit, small group session, or office or hospital visit at least once every 6 weeks, and progress review (n=280) vs. Usual care from primary care physician only (n=263)	<p>Social activities count (higher = more activities):</p> <p>Senior Care Connections vs. Usual Care: 0.50 (95% CI: 0.02, 1.0)</p> <p>SF-36 (Higher score = poorer health, Medical Outcomes Study 36-item Short Form Health Survey):</p> <p>Senior Care Connections vs. Usual Care: -0.1 (95% CI: -0.27, 0.02)</p> <p>Mediating factors:</p> <p>There was a statistically significant trend between higher number of nurses and social worker contacts, and downward change in mean number of hospital admissions, downward change in mean number of all physician visits, and downward change in mean score of Activities of Daily Living/Instrumental Activities of Daily Living (higher score = poorer activities)</p>

Abbreviation: CI = confidence interval; COPD = chronic obstructive pulmonary disease; ED = emergency department; MD = mean deviation; n = number; NR = not reported; OR = odds ratio; PROMIS = Patient-Reported Outcomes Measurement Information System; SD = standard deviation; SWCM = social worker-led case management

Table D.2. Characteristics of included primary studies: Prospective cohort studies

Author, Year	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Fabius, 2020 ³³	12 months	<p><u>Population:</u> Aged 65 years and older who transitioned from a nursing home to the community</p> <p><u>Age:</u> >65 years</p> <p><u>Geography:</u> Connecticut</p> <p><u>Race/Ethnicity:</u> White: 77.5%</p> <p><u>Sex:</u> Female: 65.7%</p> <p><u>Comorbidities:</u> NR</p> <p><u>Social Situation:</u> Issues with spouse, family, friends: 10.7%</p> <p><u>Clinical Needs:</u> Dementia/Cognitive issues: 20.6%, activities of daily living and instrumental activities of daily living impairment: mean (SD): 7.28 (6.4)</p>	Hourly personal care attendant, who provides multiple services on an hourly basis several times a week and is not restricted to the types of tasks: assisting with both activities of daily living and instrumental activities of daily living, including personal care, housekeeping, meals, companionship, and transportation (n=211) vs. Live-in personal care attendant, who resides in the home of an older adult with complex health conditions(n=211): assisting with both activities of daily living and instrumental activities of daily living, including personal care, housekeeping, meals, companionship, and transportation vs. Traditional home and community-based services provided by multiple care workers at different times: homemaking, companion, home health aide, home delivered meals, and/or adult day services, provided by multiple care workers (n=255)	<p>Hospital readmission: hourly vs. traditional home and community-based services: OR: 0.43 (95% CI: 0.21, 0.87); live-in vs. home and community-based services OR: 0.29 (95% CI: 0.13, 0.64)</p> <p>Choice and control in daily activities: hourly vs. traditional home and community-based services: OR: 0.46 (95% CI: 0.28, 0.75); live-in vs. traditional home and community-based services: OR: 0.55 (95% CI: 0.33, 0.92)</p>

Author, Year	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Holburn, 2004; ³⁴	37 months	<u>Population:</u> Intellectual disabilities and challenging behavior <u>Age:</u> Mean (SD) (range): 38.6 (9.1) (19-61) years <u>Geography:</u> New York <u>Race/Ethnicity:</u> NR <u>Sex:</u> Female: 23.1% <u>Comorbidities:</u> Psychiatric diagnosis: 52.6% <u>Social Situation:</u> NR <u>Clinical Needs:</u> Challenging behavior required specialized or intensive services that were not generally available from community residential service providers (e.g., aggression, self-injury, destruction of property, pica, running away, and inappropriate sexual behaviors)	Person-centered planning: an individual service planning team led by a facilitator, interagency planning and coordination, team planning (introduction, development of a personal profile, creation of a vision of the future, and follow-along) (n=20) vs. Conventional individual service planning: interdisciplinary teams who meet quarterly in the developmental center to discuss assessments, review progress toward service plan goals, and develop new written habilitative goals and methodologies to be pursued over the ensuing weeks and months (n=18)	Moved from institutional living to a community living arrangement: person-centered planning vs. conventional individual service planning: RR 3.41 (95% CI: 1.61, 7.24) The Outcome Index: (encompasses subscales for Autonomy and Choice Making, Home, Work and Day Activities, Health, Relationships, Community Places, Respect, Competence, and Satisfaction) person-centered planning group's Outcome Index scores increased, on average, 0.6 points (on a 5-point scale), which was approximately six times as much as the Outcome Index scores of the control group.

Abbreviation: CI = confidence interval; n = number; NR = not reported; OR = odds ratio; SD = standard deviation

Table D.3. Characteristics of included primary studies: Retrospective cohort studies

Author, Year	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Coppa, 2022³⁵	54 months	<p><u>Population:</u> Elderly with chronic conditions</p> <p><u>Age:</u> Mean (SD): 62.65 (17.23) years</p> <p><u>Geography:</u> Rhode Island</p> <p><u>Race/ethnicity:</u> NR</p> <p><u>Sex:</u> Female 67.88%</p> <p><u>Comorbidities:</u> Chronic pulmonary disease: 44%, Congestive heart failure: 19.7%, Renal Disease: 16.3%, Diabetes with chronic complications: 13.3%, Malignancy: 11.1%, Myocardial Infarction: 4.9%, and Peptic Ulcer Disease: 1.7%</p> <p><u>Social Situation:</u> NR</p> <p><u>Clinical Needs:</u> Patients have difficulties accessing clinics and face challenges with traveling to the clinic</p>	Home-based prepalliative care (HBPC): delivered by nurse practitioners in the home-based settings, services include preventative acute and chronic illness care, along with health promotion services (n=233); vs. Clinic-based prepalliative care: Delivered by nurse practitioners, physician assistants, and physicians in the clinic-based settings, services include preventative acute and chronic illness care, along with health promotion services (n=234)	<p>Mortality: HBPC vs. clinic-based prepalliative care: 41 (17.6%) vs 20 (8.5%), p=0.004</p> <p>Hospitalization: HBPC vs. clinic-based prepalliative care: Mean (SE) 0.3 (0) vs 0.7 (0.1), p<0.001</p> <p>ED visits: HBPC vs. clinic-based prepalliative care: Mean (SE) 0.4 (0.1) vs 0.7 (0.1), p<0.001</p>

Author, Year	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Wang, 2019 ³⁶	2 months	<p>Population: Older adults (≥65 years), home-healthcare admission within 48 hours since hospital discharge, and receiving ≥1 home healthcare visit in the 60-day episode</p> <p><u>Age</u>: Mean (SD): 79 (8.4) years</p> <p><u>Geography</u>: New York</p> <p><u>Race/Ethnicity</u>: White: 82%, African American: 14%</p> <p><u>Sex</u>: Female: 52%</p> <p><u>Comorbidities</u>: Hypertension: 72%, Heart failure: 22%, Diabetes: 32%, Osteoarthritis: 24%, COPD: 11%, Cognitive impairment: 78%, Daily interfering pain: 71%, Depressive symptoms: 22%, Smoking: 18%, Obesity: 18%, Exhaustion: 47%</p> <p><u>Social Situation</u>: Married: 48%, Live alone: 27%</p> <p><u>Clinical Needs</u>: Receiving daily assistance from informal caregiver: 87%, High functional limitation: 49%</p>	Interventions include skilled nursing, physical therapy, occupational therapy, or home health aide (n=1,377) vs. No HCBS interventions	<p>Hospital readmission:</p> <p>>1 weekly physical therapy visit vs. no physical therapy visit: HR: 0.18 (95% CI: 0.09, 1.36); >2 weekly skilled nurse visit vs. <1 weekly skilled nurse visit: HR: 0.52 (95% CI: 0.31, 0.87)</p> <p>Home health aide and occupational health was not significantly associated with hospital readmission</p> <p>Mediating factors:</p> <p>Greater physical therapy intensity reduced the hazard of rehospitalization in low and high functional limitation groups</p> <p>Greater skilled nursing intensity only reduced the hazard of rehospitalization in the low functional limitation group</p>

Author, Year	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Matzke, 2018³⁷	12 months	<p><u>Population:</u> Adults aged ≥60 years with ≥2 of 7 targeted chronic conditions (Congestive Heart Failure, Hypertension, Hyperlipidemia, Diabetes, Asthma, Chronic Obstructive Pulmonary Disease, Depression) taking ≥4 medications</p> <p><u>Age:</u> Mean: 65.4 years</p> <p><u>Geography:</u> Southwest Virginia</p> <p><u>Race/Ethnicity:</u> White: 87.6%, Black: 11.4%, Hispanic: 0.45%, Other: 0.55%</p> <p><u>Sex:</u> Female: 57.6%</p> <p><u>Comorbidities:</u> Diabetes: 55.8%, Hypertension: 84.1%, Hyperlipidemia: 79.35%</p> <p><u>Social Situation:</u> NR</p> <p><u>Clinical Needs:</u> ≥2 of 7 targeted chronic conditions (Congestive Heart Failure, Hypertension, Hyperlipidemia, Diabetes, Asthma, Chronic Obstructive Pulmonary Disease, Depression) taking ≥4 medications</p>	Pharmacist-physician collaborative care: clinical pharmacists embed in the care team providing comprehensive medication management and chronic disease state management through quarterly phone calls (n=2,480) vs. Usual Care (n=2,480)	<p>Hospitalization: Pharmacist-physician collaborative care vs. usual care: significant reduction (23.4% vs. 8.7%; p<0.0001)</p> <p>HbA1C (%): pharmacist-physician collaborative care vs. usual care: Mean change 0.46 (95% CI: 0.33, 0.58) vs. 0.08 (95% CI: -0.02, 0.18); p<0.0001</p> <p>Systolic blood pressure (mm Hg): Mean change 6.28 (95% CI: 4.88, 7.68) vs. 1.05 (95% CI: -0.20, 2.30); p<0.0001</p> <p>LDL cholesterol (mg/dL): Mean change 3.72 (95% CI: 0.88, 6.57) vs. 4.15 (95% CI: 1.66, 6.64); p=0.83</p> <p>Diastolic blood pressure (mm Hg): Mean change 2.69 (95% CI: 1.99, 3.39) vs. 1.23 (95% CI: 0.51, 1.94); p<0.01</p> <p>Total cholesterol (mg/dL): Mean change 5.08 (95% CI: 1.67, 8.49) vs. 5.34 (95% CI: 2.43, 8.25); p=0.91</p>
Schubert, 2016³⁸	12 months	<p><u>Population:</u> Hospitalized veterans, aged 65 or older, live at home or in assisted living, enrolled in primary care at Indianapolis Veterans Affairs Medical Center, not on dialysis, and life expectancy of at least 6 months</p> <p><u>Age:</u> Mean (range) 77.7 (65-97) years</p> <p><u>Geography:</u> Marion County, Indiana</p> <p><u>Race/Ethnicity:</u> NR</p> <p><u>Sex:</u> Female: 3.9%</p> <p><u>Comorbidities:</u> NR</p> <p><u>Social Situation:</u> NR</p> <p><u>Clinical Needs:</u> NR</p>	Geriatric Resources for Assessment and Care of Elders program (GRACE): simplifying medication regimens, arranging for in-home nursing medication assistance, consulting physical therapy, obtaining needed durable medical equipment for the home, starting or adjusting an antidepressant, and addressing caregiver stress and burden (n=179) vs. No-Geriatric Resources for Assessment and Care of Elders program (Control) (n=77)	<p>30-day readmissions: GRACE vs. Control: -13.1% (95% CI: -36.4%, 10.2%)</p> <p>Admissions/100 veterans/year: GRACE vs. Control: 44.1 (95% CI: -110.7, 22.5)</p> <p>Bed days/100 veterans/year: GRACE vs. Control: -221.4 (95% CI: -362.7, -80.1)</p> <p>ED visits/100 veterans/year: GRACE vs. Control: -19.4 (95% CI: -111.2 to 72.4)</p>

Author, Year	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Foltz, 2014 ³⁹	6 months	<u>Population:</u> Individuals at high risk of poorer health outcomes or frequent hospital utilization <u>Age:</u> Mean (SD) 61.62 (23.96) years <u>Geography:</u> Pennsylvania <u>Race/Ethnicity:</u> White: 96.4% <u>Sex:</u> Female: 56.3% <u>Comorbidities:</u> Diabetes: 33.6%, Cardiac disease: 44.6% <u>Social Situation:</u> NR <u>Clinical Needs:</u> High risk of poorer health outcomes or frequent hospital utilization	Community care teams (CCT): population health management, disease self-management and goal setting skills, addressing behavioral health, social, and economic problems, and connecting the patient to other Network and community resources as needed, contacting patients via the telephone within 48 business hours of discharge from the hospital to reconcile medications, assess and identify issues for followup, answer patient questions and coordinate appropriate appointments (n=406) vs. No community care teams (No-CCT): (n=406)	30-day readmissions: CCT vs. No-CCT: 0 vs. 0 ED visits: No significant change for both groups Satisfaction: There was no change in patient satisfaction, although after 12 months the “always” response for following up on lab tests was no longer higher than the national comparison and helpfulness of staff rated “never/sometimes” was below the national comparison

Abbreviation: CCT = community care team; CI = confidence interval; COPD = chronic obstructive pulmonary disease; ED = emergency department; GRACE = Geriatric Resources for Assessment and Care of Elders program; HCBS = home and community-based services; HR = hazard ratio; n = number; NR = not reported; SE = standard error; SD = standard deviation

Table D.4. Characteristics of included primary studies: Cross-sectional surveys

Author, Year	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Chong, 2024⁴⁰	<p><u>Population:</u> Older adults and adults with physical disabilities receiving Medicaid HCBS</p> <p><u>Age:</u> <55 years: 23%, 55-64 years: 27%, 65-74 years: 23%, 75-84 years: 17%, 85+ years: 10%</p> <p><u>Geography:</u> 12 U.S. States: Colorado, Indiana, Kansas, Mississippi, Nebraska, New Jersey, Ohio, South Dakota, Tennessee, Utah, Vermont, and Wisconsin</p> <p><u>Race/Ethnicity:</u> White: 60%, Black: 27%, Hispanic: 3%, Other: 5%, Unknown: 6%</p> <p><u>Sex:</u> Female: 66%</p> <p><u>Alzheimer's/dementia:</u> 9%</p> <p><u>Clinical Needs:</u> Self-care needs: None 23%, Some 44%, A lot 37% Other daily activity needs: None 5%, Some 43%, A lot 52%</p> <p><u>Social Situation:</u> congregate setting: 18%, home/senior living: 81%; other: 1%</p>	<p>Person-centered planning in Medicaid HCBS: decision-making, service plan reflected preferences/choices</p>	<p><u>Satisfaction:</u> Person involved in decision making and service plan reflected person's preferences and choices were associated with significantly higher satisfaction.</p> <p><u>Social isolation:</u> Person involved in decision making and service plan reflected person's preferences and choices were significantly more likely to be involved in community (active in community and interaction with family and friends).</p> <p><u>Choice and control:</u> Person involved in decision making and service plan reflected person's preferences and choices were significantly more likely to feel in control of life.</p>

Author, Year	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Isvan, 2023 ⁴¹	<p><u>Population</u>: Adults with intellectual and developmental disability who received one paid HCBS and case management</p> <p><u>Geography</u>: 37 U.S. States</p> <p><u>Race/Ethnicity</u>: Non-Hispanic Whites (73%);</p> <p><u>Sex</u>: Females: 43%</p> <p><u>Social Situation</u>: Congregate setting 38%, in their own home 17%, a relative's home 38%, a foster/host home 8%</p> <p><u>Clinical Needs</u>: Intellectual and developmental disability</p>	Existing factors in person-centered planning: case managers accessibility and attentiveness, person-centered content of service plans vs. Missing factors in person-centered planning	<p>Perceived control over life decisions: Case managers' (CM) accessibility and attentiveness to individual preferences were significantly associated with perceived control over life decisions.</p> <p>Sense of health and well-being: CM accessibility and attentiveness to individual preferences were significantly associated with sense of health and well-being</p>
Chong, 2022 ⁴²	<p><u>Population</u>: Older adults and adults with physical disabilities receiving Medicaid HCBS</p> <p><u>Age</u>: 18-54 years: 22%, 55-64 years: 22%, 65-74 years: 23%, 75-84 years: 19%, 85+ years: 14%</p> <p><u>Geography</u>: 13 U.S. States: Colorado, Indiana, Kansas, Minnesota, Mississippi, Nebraska, New Jersey, Nevada, Oregon, Tennessee, Texas, Vermont, Wisconsin</p> <p><u>Race/Ethnicity</u>: White: 55%, Black: 19%, Hispanic: 14%, Other: 6%, Unknown: 6%</p> <p><u>Sex</u>: Female: 64%</p> <p><u>Comorbidities</u>: NR</p> <p><u>Social Situation</u>: 94% live in urban areas, 80% live in home/senior living, 32% live alone</p> <p><u>Clinical Needs</u>: Self-care needs: None 19%, Some 44%, A lot 37% Other daily activity needs: None 5%, Some 59%, A lot 36%</p>	Any unmet need for HCBS: Medicaid HCBS recipients with any unmet need across 5 domains: 1) assistance with daily activities 2) assistive technology 3) home modifications 4) transportation and 5) services that fully meet needs and goals (n=8,040) vs. No unmet need for HCBS: Medicaid HCBS recipients reporting no unmet need in any of those 5 domains (n=1,873)	<p>ED visit: Any unmet need was associated with greater likelihood of an ED visit (52% vs. 34%)</p> <p>Hospital/rehab stay: Any unmet need was associated with greater likelihood of hospital/rehab stay (36% vs. 24%)</p> <p>Satisfaction: Any unmet needs were associated with the lowest likelihood of user satisfaction with how time is spent (55% vs. 80%)</p> <p>In control of life: Any unmet needs were associated with the lowest likelihood of user control of life (64% vs. 84%)</p>

Author, Year	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Liang, 2017 ⁴³	<p><u>Population</u>: Adults aged ≥65 with at least 1 chronic condition</p> <p><u>Age</u>: Mean 74.3 years</p> <p><u>Geography</u>: Nationally representative of U.S</p> <p><u>Race/Ethnicity</u>: Non-Hispanic White: 80%</p> <p><u>Sex</u>: Female: 56%</p> <p><u>Comorbidities</u>: Number of chronic conditions: 3, Multiple (≥2) chronic conditions: 91%</p> <p><u>Social Situation</u>: NR</p> <p><u>Clinical needs</u>: at least 1 chronic condition</p>	<p>Patient-centered care: included whole-person care orientation, patient engagement in care, and enhanced access to care (n=5,963) vs. Partial patient-centered care: included whole-person care orientation, and at least 1 item of patient engagement in care or enhanced access to care (n=6,973) vs. Nonpatient-centered care (n=3,718)</p>	<p>Blood pressure check: Patient-centered care vs. Nonpatient-centered care: OR: 1.28 (95% CI: 0.98, 1.83)</p> <p>Partial Patient-centered care vs. Nonpatient-centered care: OR: 1.43 (95% CI: 1.09, 1.99)</p> <p>Cholesterol check: Patient-centered care vs. Nonpatient-centered care: OR: 2.00 (95% CI: 1.58, 2.56)</p> <p>Partial Patient-centered care vs. Nonpatient-centered care: OR: 1.69 (95% CI: 1.38, 2.09)</p> <p>Routine checkup: Patient-centered care vs. Nonpatient-centered care: 1.81 (95% CI: 1.50, 2.20)</p> <p>Partial Patient-centered care vs. Nonpatient-centered care: 1.45 (95% CI: 1.24, 1.70)</p>

Author, Year	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Liang, 2017⁴³ (continued)	<u>Population:</u> Adults aged ≥65 with at least 1 chronic condition <u>Age:</u> Mean 74.3 years <u>Geography:</u> Nationally representative of U.S <u>Race/Ethnicity:</u> Non-Hispanic White: 80% <u>Sex:</u> Female: 56% <u>Comorbidities:</u> Mean 3.9 chronic conditions, 91% with multiple (≥2) chronic conditions <u>Social Situation:</u> NR <u>Clinical Needs:</u> at least 1 chronic condition	Patient-centered care: included whole-person care orientation, patient engagement in care, and enhanced access to care (n=5,963) vs. Partial patient-centered care: included whole-person care orientation, and at least 1 item of patient engagement in care or enhanced access to care (n=6,973) vs. Nonpatient-centered care (n=3,718)	Blood stool test: Patient-centered care vs. Nonpatient-centered care: OR: 1.84 (95% CI: 1.54, 2.26) Partial Patient-centered care vs. Nonpatient-centered care: OR: 1.70 (95% CI: 1.44, 2.01) Breast exam: Patient-centered care vs. Nonpatient-centered care: OR: 1.52 (95% CI: 1.29, 1.77) Partial Patient-centered care vs. Nonpatient-centered care: OR: 1.40 (95% CI: 1.16, 1.64) Mammogram: Patient-centered care vs. Nonpatient-centered care: OR: 1.55 (95% CI: 1.36, 1.96)

Author, Year	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Liang, 2017⁴³ (continued)	<u>Population:</u> Adults aged ≥65 with at least 1 chronic condition <u>Age:</u> Mean 74.3 years <u>Geography:</u> Nationally representative of U.S <u>Race/Ethnicity:</u> Non-Hispanic White: 80% <u>Sex:</u> Female: 56% <u>Comorbidities:</u> Mean 3.9 chronic conditions, 91% with multiple (≥2) chronic conditions <u>Social Situation:</u> NR <u>Clinical Needs:</u> at least 1 chronic condition	Patient-centered care: included whole-person care orientation, patient engagement in care, and enhanced access to care (n=5,963) vs. Partial patient-centered care: included whole-person care orientation, and at least 1 item of patient engagement in care or enhanced access to care (n=6,973) vs. Nonpatient-centered care (n=3,718)	Partial Patient-centered care vs. Nonpatient-centered care: OR: 1.39 (95% CI: 1.14, 1.63) Pap smear test: Patient-centered care vs. Nonpatient-centered care: OR: 3.34 (95% CI: 2.18, 4.88) Partial Patient-centered care vs. Nonpatient-centered care: OR: 3.97 (95% CI: 2.74, 5.76) Healthy diet education: Patient-centered care vs. Nonpatient-centered care: OR: 1.31 (95% CI: 1.09, 1.50) Partial Patient-centered care vs. Nonpatient-centered care: OR: 1.10 (95% CI: 0.88, 1.28)

Author, Year	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Liang, 2017 ⁴³ (continued)	<u>Population:</u> Adults aged ≥65 with at least 1 chronic condition <u>Age:</u> Mean 74.3 years <u>Geography:</u> Nationally representative of U.S <u>Race/Ethnicity:</u> Non-Hispanic White: 80% <u>Sex:</u> Female: 56% <u>Comorbidities:</u> Mean 3.9 chronic conditions, 91% with multiple (≥2) chronic conditions <u>Social Situation:</u> NR <u>Clinical Needs:</u> at least 1 chronic condition	Patient-centered care: included whole-person care orientation, patient engagement in care, and enhanced access to care (n=5,963) vs. Partial patient-centered care: included whole-person care orientation, and at least 1 item of patient engagement in care or enhanced access to care (n=6,973) vs. Nonpatient-centered care (n=3,718)	Physical activity education: Patient-centered care vs. Nonpatient-centered care: OR: 1.24 (95% CI: 1.09, 1.41) Partial Patient-centered care vs. Nonpatient-centered care: OR: 1.03 (95% CI: 0.84, 1.22) Mediating factors: Sex: Females were less likely than males to receive cholesterol checks (OR: 0.86, 95% CI: 0.73, 0.99) and blood stool tests (OR: 0.83, 95% CI: 0.72, 0.90) Age: 1-year increase of age was associated with a 2% higher odds of receiving blood pressure checks (OR: 1.02, 95% CI: 1.01, 1.07) and a 3% higher odds of receiving routine checkups (OR: 1.03, 95% CI: 1.01, 1.06).

Author, Year	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Liang, 2017 ⁴³ (continued)	<p><u>Population</u>: Adults aged ≥65 with at least 1 chronic condition</p> <p><u>Age</u>: Mean 74.3 years</p> <p><u>Geography</u>: Nationally representative of U.S</p> <p><u>Race/Ethnicity</u>: Non-Hispanic White: 80%</p> <p><u>Sex</u>: Female: 56%</p> <p><u>Comorbidities</u>: Mean 3.9 chronic conditions, 91% with multiple (≥2) chronic conditions</p> <p><u>Social Situation</u>: NR</p> <p><u>Clinical Needs</u>: at least 1 chronic condition</p>	<p>Patient-centered care: included whole-person care orientation, patient engagement in care, and enhanced access to care (n=5,963) vs. Partial patient-centered care: included whole-person care orientation, and at least 1 item of patient engagement in care or enhanced access to care (n=6,973) vs. Nonpatient-centered care (n=3,718)</p>	<p>Race/ethnicity: Varied according to racial group</p> <p>Marriage status: Being married was associated with higher odds of receiving cholesterol check (OR: 1.28, 95% CI: 1.10, 1.56), breast exam, mammogram, and healthy diet education.</p> <p>Education level: advanced degree was associated with higher odds of receiving blood pressure check, cholesterol check, routine checkup, blood stool test.</p> <p>Household per capita income: U.S. \$50,000 and more was significantly associated with higher odds of getting blood pressure check, cholesterol check, routine checkup, breast exam, and mammogram.</p> <p>Insurance: Medicare plus private insurance was associated with higher odds of receiving blood pressure tests, routine checkups, and mammograms.</p> <p>Managed care status: Having managed care was associated with higher odds of receiving mammograms and Pap tests.</p>

Author, Year	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Stancliffe, 2009 ⁴⁴	<p><u>Population</u>: Adults with intellectual and developmental disabilities receiving Medicaid HCBS or Intermediate Care Facility (ICF/IID) services</p> <p><u>Age</u>: (mean) 43.08 years</p> <p><u>Geography</u>: 6 U.S. States: Alabama, Indiana, Kentucky, Massachusetts, Oklahoma, Wyoming</p> <p><u>Race/Ethnicity</u>: NR</p> <p><u>Sex</u>: Female: 44.3%</p> <p><u>Comorbidities</u>: Psychiatric diagnosis: 35.4%, Autism: 3.6%, Cerebral palsy: 12.1%, Seizure/neurological disorder: 22.4%</p> <p><u>Social Situation</u>: ICF/IID: 72.6% in congregate facilities/group homes, HCBS: 48.8% own home or with family</p> <p><u>Clinical Needs</u>: Intellectual and developmental disabilities</p>	<p>HCBS: Medicaid HCBS recipients (n=1,556) vs. ICF/IID: Medicaid Intermediate Care Facilities (n=325)</p>	<p>Loneliness: HCBS vs. ICF/IID: 55.1% vs. 48.4% (p>0.05)</p> <p>Mediating factors Being less lonely was associated with smaller settings, living with family, and choosing living companions</p>

Author, Year	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Wiener, 2007 ⁴⁵	<p><u>Population</u>: Older people and younger adults with physical disabilities, as well as individuals with intellectual and developmental disabilities who are Medicaid HCBS beneficiaries</p> <p><u>Age</u>: Younger than 44 years: 12.5%, 45 - 64 years: 32.2%, 65 - 74 years: 21.1%, 75 - 84 years: 21.7%, 85 years and older: 12.2%</p> <p><u>Geography</u>: Washington State</p> <p><u>Race/Ethnicity</u>: White: 75.6%, Black: 7.5%, Asian: 13.8%, Other race: 3.1%</p> <p><u>Sex</u>: Female: 72.9%</p> <p><u>Comorbidities</u>: NR</p> <p><u>Social Situation</u>: Social participation: 80.4%, Live in a group setting: 17.8%</p> <p><u>Clinical Needs</u>: Fair/poor health: 68.4%, Mean number of instrumental activities of daily living limitations (0 to 4 scale): 3.402, Mean number of activities of daily living limitations (0 to 6 scale): 2.703, Having unmet needs for activities of daily living and instrumental activities of daily living: 70.9%, Some or great deal of pain: 86.4%, Having pressure sores: 10.1%, Bladder/bowel difficulties: 63%</p>	Consumer-directed home care: individuals hire, train, supervise, and fire the home care worker (n=228) vs. Agency-directed home care: individuals do not hire, train, direct, or fire the workers who provide their care (n=285)	<p>Mean Satisfaction With Paid Personal Assistance Scale (8-item scale ranging from 0–100):</p> <p>Overall sample: Consumer-directed home care: 94.05 vs. Agency-directed home care: 91.28 (p<0.05)</p> <p>Younger than 65 years: Consumer-directed home care: 91.65 vs. Agency-directed home care: 88.68 (p>0.05)</p> <p>Older than 65 years: Consumer-directed home care: 96.84 vs. Agency-directed home care: 92.82 (p<0.05)</p>

Author, Year	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Wiener, 2007⁴⁵ (continued)	<p><u>Population:</u> Older people and younger adults with physical disabilities, as well as individuals with intellectual and developmental disabilities who are Medicaid HCBS beneficiaries</p> <p><u>Age:</u> Younger than 44 years: 12.5%, 45 - 64 years: 32.2%, 65 - 74 years: 21.1%, 75 - 84 years: 21.7%, 85 years and older: 12.2%</p> <p><u>Geography:</u> Washington State;</p> <p><u>Race/Ethnicity:</u> White: 75.6%, Black: 7.5%, Asian: 13.8%, Other race: 3.1%;</p> <p><u>Sex:</u> Female: 72.9%</p> <p><u>Comorbidities:</u> NR</p> <p><u>Social participation:</u> 80.4%, Live in a group setting: 17.8%</p> <p><u>Clinical Needs:</u> Fair/poor health: 68.4%, Mean number of instrumental activities of daily living limitations (0 to 4 scale): 3.402, Mean number of activities of daily living limitations (0 to 6 scale): 2.703, Having unmet needs for activities of daily living and instrumental activities of daily living: 70.9%, Some or great deal of pain: 86.4%, Having pressure sores: 10.1%, Bladder/bowel difficulties: 63%</p>	Consumer-directed home care: individuals hire, train, supervise, and fire the home care worker (n=228) vs. Agency-directed home care: individuals do not hire, train, direct, or fire the workers who provide their care (n=285)	<p>Mediating factors</p> <p>Overall sample: Being younger than age 44 years (compared with aged 65 to 74 years), male sex, and unmet activities of daily living and instrumental activities of daily living needs were significant negative predictors of satisfaction</p> <p>Younger than 65 years: only unmet activities of daily living and instrumental activities of daily living needs was a significant negative predictor of satisfaction</p> <p>Older than 65 years: Consumer direction and number of activities of daily living limitations were positive significant predictors of higher satisfaction with paid care. Incontinence, and number of unmet activities of daily living and instrumental activities of daily living needs were significant negative predictors of satisfaction</p>

Abbreviation: CI = confidence interval; CM = case manager; ED = emergency department; HCBS = home and community-based services; ICF/IID = Intermediate Care Facilities for Individuals with Intellectual Disabilities; n = number; NR = not reported; OR = odds ratio; U.S. = United States

Table D.5. Characteristics of included primary studies: Pre/Post studies

Author, Year	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Kennedy-Hendricks, 2021 ⁴⁶	3 months	<p><u>Population</u>: Medicaid enrollees with serious mental illness</p> <p><u>Age</u>: Mean (range): 42.2 (21-64) years</p> <p><u>Geography</u>: Maryland</p> <p><u>Race/Ethnicity</u>: Black: 56.3%, White: 38.3%, other: 5.4%</p> <p><u>Sex</u>: Female: 56.4%</p> <p><u>Comorbidities</u>: Schizophrenia: 43.2%, Bipolar disorder: 33.1%, Major depressive disorder: 22.7%, Substance use disorder: 26.1%, Charlson index: mean (SD): 0.8 (1.5)</p> <p><u>Social Situation</u>: NR</p> <p><u>Clinical Needs</u>: Enrolled in Medicaid, >5 claims of psychiatric rehabilitation program services, serious mental illness</p>	Maryland's behavioral health homes: health home services delivery, including somatic care coordination and management, transitional care, health promotion, referrals, and individual and family support (n=3,382) vs. No behavioral health homes (n=8,850)	<p>Hospital readmission within 7 days of discharge from a mental illness-related hospitalization: RD: -0.001 (95% CI: -0.002, 0.001);</p> <p>Hospital readmission within 30 days of discharge from a mental illness-related hospitalization: RD: -0.000 (95% CI: -0.002, 0.002);</p> <p>Hospital readmission within 7 days of discharge from a somatic hospitalization: RD: -0.000 (95% CI: -0.001, 0.001);</p> <p>Hospital readmission within 30 days of discharge from a somatic hospitalization: RD: -0.001 (95% CI: -0.003, 0.001)</p>

Author, Year	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Fleisher, 2018 ⁴⁷	12 months	<p><u>Population:</u> Individuals with a diagnosis of Parkinson's disease, Parkinson's disease Dementia, Dementia with Lewy Bodies, or an atypical parkinsonism</p> <p><u>Age:</u> Median (IQR) 79.6 (72.5-84.8) years</p> <p><u>Geography:</u> New York City</p> <p><u>Race/Ethnicity:</u> White: 85.9%, Black: 7.1%, Asian: 7.1%, Hispanic: 15.3%</p> <p><u>Sex:</u> Female: 51.8%</p> <p><u>Comorbidities:</u> Parkinson's disease: 78.8%, Atypical Parkinson's: 7.1%, Dementia with Lewy bodies: 4.7%, Progressive Supranuclear Palsy: 4.7%, Multiple System Atrophy: 2.4%, Corticobasal syndrome: 1.2%, Huntington's disease: 1.2%</p> <p><u>Social Situation:</u> NR</p> <p><u>Clinical Needs:</u> Hoehn & Yahr Stage distribution: Bilateral disease with normal balance: 4.7%, Mild-moderate disease with impaired balance: 25.9%, Severe disease and stands unassisted: 37.7%, Wheelchair: 31.8%</p>	Home visit care: interdisciplinary home visit team (movement disorders-trained neurologist, social worker, and nurse) with team-based medical treatment, psychosocial support, and health education (n=61) vs. Prior to home visit care (n=85)	<p>Hospitalization: Post-home visit care vs. prior to home visit care: OR: 0.81 (95% CI: 0.41, 1.59)</p> <p>ER visit: Post-home visit care vs. prior to home visit care: OR: 0.90 (95% CI: 0.44, 1.84)</p>

Author, Year	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Sudat, 2018 ⁴⁸	48 months	<p><u>Population:</u> People who have high disease burden with distressing symptoms that negatively affect their quality of life, plus one of the following: rapid/significant functional/nutritional decline, recurrent/unplanned hospitalizations/emergency department visits, likely to die in the next 12 months (according to the referring clinician), or hospice appropriate, but decline hospice services</p> <p><u>Age:</u> 69 - 78 years: 29.3%, 79 - 88 years: 41%, +89 years: 29.6%</p> <p><u>Geography:</u> Northern California</p> <p><u>Race/Ethnicity:</u> White: 78.8%</p> <p><u>Sex:</u> Female: 53.4%</p> <p><u>Comorbidities:</u> Chronic pulmonary disease: 59%, Cerebrovascular disease: 40%, Dementia: 23.2%, Malignancy: 25%, Peripheral vascular disease: 28%, Renal disease: 48.4%</p> <p><u>Social Situation:</u> NR</p> <p><u>Clinical Needs:</u> High disease burden with distressing symptoms that negatively affect their quality of life, plus one of the following: rapid/significant functional/nutritional decline, recurrent/unplanned hospitalizations/emergency department visits, likely to die in the next 12 months</p>	Advanced Illness Management program: palliative care within home health, physician- and call-center-based telephonic support, hospital-based care liaisons, and nursing and social work home visits for people not eligible for home health (n=1,692) vs. Nonadvanced Illness management program controls (n=6,246)	<p>Mortality in the ICU: Advanced Illness Management vs. controls: attributable difference -7.1% (95% CI: -8.9%, -5.2%)</p> <p>Mortality in the hospital: Advanced Illness Management vs. controls: attributable difference -8.2% (95% CI: -10.8%, -5.5%)</p> <p>Hospice enrollment in the final 30 days: Advanced Illness Management vs. controls: attributable difference 17.9% (95% CI: 14.7%, 21%)</p> <p>Inpatient days in the final 30 days: Advanced Illness Management vs. controls: attributable differences in utilization per 1000 beneficiaries: -1361.3 (95% CI: -1725.0, -997.6)</p> <p>ED visits: Advanced Illness Management vs. controls: attributable differences in utilization per 1000 beneficiaries: -21.6 (95% CI: -58.0, 14.8)</p>

Author, Year	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Szanton, 2015 ⁴⁹	5 months	<p><u>Population:</u> Community-dwelling older adults aged ≥65 with difficulty in ≥1 activities of daily living</p> <p><u>Age:</u> Mean (SD): 74.1 (6.9) years</p> <p><u>Geography:</u> Baltimore, Maryland and surrounding counties</p> <p><u>Race/Ethnicity:</u> White: 15%, Black: 83%, Other: 2%</p> <p><u>Sex:</u> Female: 87%</p> <p><u>Comorbidities:</u> Number of chronic conditions: Mean (SD): 3.5 (1.3)</p> <p><u>Social Situation:</u> Lived alone: 49%</p> <p><u>Clinical Needs:</u> Activity of daily living difficulties: Mean (SD): 4.1 (2.0)</p>	Community Aging in Place, Advancing Better Living for Elders (CAPABLE): patient-directed, team-based intervention 1) comprising an occupational therapist, a registered nurse, and a handyman; and 2) including assessment, education, interactive problem-solving, and clinicians clinically customized content to each participant's self-identified needs and goals (n=100) vs. Prior to CAPABLE	<p>Activity of daily living limitations improved in 79% of the 100 adults.</p> <p>For those with depressive symptoms at the baseline visit (PHQ-9 score ≥5, n=60), depressive symptoms were reduced from an average severity score of 10.1 to 6.3; a magnitude of difference that is clinically significant.</p> <p>Home hazards (e.g., slippery rugs, low toilet seats, missing handrails) decreased by half from mean (SD): 3.5 (2.0) to 1.5 (1.3)</p>
Raven, 2011 ⁵⁰	24 months	<p><u>Population:</u> Medicaid patients aged 18-64 years predicted to be at high risk for hospital readmission</p> <p><u>Age:</u> Mean age (range) 53 (39-64) years</p> <p><u>Geography:</u> New York City</p> <p><u>Race/Ethnicity:</u> White: 47%, African American: 16%, Hispanic 32%</p> <p><u>Sex:</u> Female: 0%</p> <p><u>Comorbidities:</u> Hypertension: 47%, Chronic obstructive pulmonary disease/asthma: 37%, Hepatitis B/C: 37%, Seizure disorder: 26%, Coronary artery disease/Myocardial infraction: 21%, Diabetes: 21%, Skin conditions: 21%, Deep vein thrombosis/Pulmonary embolism: 21%, Cirrhosis: 11%, Chronic pancreatitis: 11%, Atrial fibrillation: 11%</p> <p><u>Social Situation:</u> Experiencing homelessness or marginally housed: 89%</p> <p><u>Clinical Needs:</u> Require assistance with care coordination, transportation, housing, entitlements</p>	Patient-centered care management program: a multidisciplinary intervention team, including a Community-Based Care Manager responsible for providing care management and coordination both inside and outside the hospital system (n=19) vs. Prior to the program	<p>Hospitalizations: 12 months postintervention vs. 12 months preintervention: -37.5% (from 64 admissions preintervention to 40 admission postintervention)</p> <p>ED visits: 12 months postintervention vs. 12 months preintervention: -10.4% (from 106 ED visits preintervention to 95 postintervention)</p>

Author, Year	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Fernandes, 2010⁵¹	12 months	<p><u>Population:</u> Adult patients with advanced chronic diseases who met the Medicare homebound definition; the area includes a large low-income, immigrant populations from Asia and the Pacific Islands</p> <p><u>Age:</u> Median (range) 71 (27-94) years</p> <p><u>Geography:</u> Hawaii</p> <p><u>Race/Ethnicity:</u> White: 2.2%, Samoan: 26.1%, Filipino: 21.7%, Japanese: 19.6%, Micronesian: 13.0%, Hawaiian: 6.5%, Other minority: 10.8%</p> <p><u>Sex:</u> Female: 56.5%</p> <p><u>Comorbidities:</u> Stroke, cerebral palsy: 45.7%, Cancer: 19.6%, Alzheimer's and other dementias: 10.9%, Heart disease: 6.5%, Chronic obstructive pulmonary disease and asthma: 6.5%, Renal failure: 4.3%, Morbid obesity and hepatitis: 2.2%, Failure to thrive: 2.2%, Other: 2.2%</p> <p><u>Social Situation:</u> NR</p> <p><u>Clinical Need:</u> Functional status: Dependent in instrumental activities of daily living only 30.4%, Dependent in activities of daily living and instrumental activities of daily living 69.6%. Palliative Performance Scale: 80%–100% (full ambulation & self-care): 0%, 60%–70% (unable to work, poor ambulation): 28.3%, 40%–50% (unable to work, mainly sits/lies): 58.5%, 20%–30% (bed-bound, needs total care): 15.2%</p>	Home-based palliative care program: large interdisciplinary team including a physician, a nurse, a case manager, a psychologist/pastor, interpreters, and volunteers to improve access and delivery of culturally sensitive palliative care, and reduce emotional, spiritual and physical suffering (n=46) vs. Prior to the program	<p>Survival: At the end of the study 37 (80%) of the patients were still alive</p> <p>Change in symptoms: the percentage of patients with “good” scores (less than 3 of 10) increased from 59% to 81% for anxiety and from 57% to 71% for pain</p> <p>Missoula Vitas Quality of Life: Changes in symptoms: mean (SE) 3.78 (1.75) p=0.12 Changes in functioning: mean (SE) 2.09 (1.32) p=0.16 Changes in interpersonal: mean (SE) -3.04 (2.58) p=0.28 Changes in well-being: mean (SE) 7.17 (2.40) p=0.03 Changes in transcendence: mean (SE) 4.71 (2.90) p=0.12</p> <p>Advanced directive planning: At baseline, 55% stated that they had an advanced directive, copies were in the charts for 17% only vs. end of the study, 90% stated that they had an advanced directive, copies were in the charts for 65%</p>

Author, Year	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Fernandes, 2010⁵¹ (continued)	12 months	<p><u>Population:</u> Adult patients with advanced chronic diseases who met the Medicare homebound definition; the area includes a large low-income, immigrant populations from Asia and the Pacific Islands</p> <p><u>Age:</u> Median (range) 71 (27-94) years</p> <p><u>Geography:</u> Hawaii</p> <p><u>Race/Ethnicity:</u> White: 2.2%, Samoan: 26.1%, Filipino: 21.7%, Japanese: 19.6%, Micronesian: 13.0%, Hawaiian: 6.5%, Other minority: 10.8%</p> <p><u>Sex:</u> Female: 56.5%</p> <p><u>Comorbidities:</u> Stroke, cerebral palsy: 45.7%, Cancer: 19.6%, Alzheimer's and other dementias: 10.9%, Heart disease: 6.5%, Chronic obstructive pulmonary disease and asthma: 6.5%, Renal failure: 4.3%, Morbid obesity and hepatitis: 2.2%, Failure to thrive: 2.2%, Other: 2.2%</p> <p><u>Social Situation:</u> NR</p> <p><u>Clinical Needs:</u> Functional status: Dependent in instrumental activities of daily living only 30.4%, Dependent in activities of daily living and instrumental activities of daily living 69.6%. Palliative Performance Scale: 80%–100% (full ambulation & self-care): 0%, 60%–70% (unable to work, poor ambulation): 28.3%, 40%–50% (unable to work, mainly sits/lies): 58.5%, 20%–30% (bed-bound, needs total care): 15.2%</p>	Home-based palliative care program: large interdisciplinary team including a physician, a nurse, a case manager, a psychologist/pastor, interpreters, and volunteers to improve access and delivery of culturally sensitive palliative care, and reduce emotional, spiritual and physical suffering (n=46) vs. Prior to the program	<p>Do not resuscitate orders: Percentage of clients with do not resuscitate orders increased from 50% to approximately 60%</p> <p>ED visits: 65% of patients had no emergency department preceding the study, and 67% had no emergency department visits during the study</p> <p>Hospital admissions: The percent of patients who had no acute care admissions increased from about 48% to 74% (p=0.002)</p> <p>Utilization of other services: Case management: 84.8%, Respite: 41.3%, Long-term care: 34.8%, Hospice: 26.1%, Other (meals, bathing, volunteers): 71.7%</p>

Author, Year	Length of Followup	Population; Age; Geography; Race/ethnicity; Sex; Comorbidities; Social Situation; Clinical Needs	Intervention (n) vs. Comparison (n)	Findings
Stark, 2009⁵²	24 months	<u>Population:</u> Community-dwelling older adults with functional limitations requiring activities of daily living assistance <u>Age:</u> Mean (range): 81.7 (61-95) years <u>Geography:</u> Suburban St. Louis, Missouri <u>Race/Ethnicity:</u> White: 90.7%, Black: 6.7%, Asian: 1.3%, Russian: 1.3% <u>Sex:</u> Female: 88% <u>Comorbidities:</u> NR <u>Social Situation:</u> Lived alone: 73.3% <u>Clinical Needs:</u> Functional limitations requiring activities of daily living assistance	Client-centered home modification program: home modification strategies, such as adaptive equipment, architectural modifications, major home renovations, and training in using the compensatory supports and strategies during daily activities. (n=67) vs. Prior to the program	No significant difference on Physical and cognitive changes. Satisfaction (rating of 5–10 problems identified by participant from 1 not satisfied to 10 extremely satisfied): 3 months post intervention vs. prior to intervention: 1.9 (95% CI: 1.23, 2.57) 12 months post intervention vs. prior to intervention: 1.6 (95% CI: 0.90, 2.30)
Fisher, 2007⁵³	3 months	<u>Population:</u> Frail, older adults living in assisted living <u>Age:</u> Mean (range): 80.1 (74-90) years <u>Geography:</u> Colorado <u>Race/ethnicity:</u> NR <u>Sex:</u> Female: 75% <u>Comorbidities:</u> Varied individual diagnoses like cerebral vascular accident, arthritis, macular degeneration <u>Social Situation:</u> NR <u>Clinical Needs:</u> Self-reported need for activities of daily living assistance	Short-term, home-based occupational therapy: client-centered and occupation-based intervention with one of the following approaches: 1) restorative approach to change client factors or diminished capacity in order to restore underlying body functions needed for occupational performance; 2) acquisitional approach with focus on occupational skills training, without explicit intention to remediate underlying impairments; 3) compensatory approach to provide adaptive equipment or technology, modify physical or social environments, or teach alternative ways of doing; 4) or the combination (n=8) vs. Prior to the program	The program resulted in overall improvements in activities of daily living motor but not activities of daily living process ability.

Abbreviation: CAPABLE = Community Aging in Place, Advancing Better Living for Elders intervention; CI = confidence interval; ED = emergency department; ICU = intensive care unit; n = number; NR = not reported; OR = odds ratio; RD = risk difference; SE = standard error; SD = standard deviation

Appendix E. Appendix References

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